

The Missouri Greenbook

Living with Brain Injury



A guide for survivors, families and caregivers

Missouri
DHSS
Department of Health
and Senior Services

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Medical information

You might find it helpful to keep important health-related information readily available.

This book belongs to: _____

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Diagnosis: _____

Health care providers:

Name of hospital: _____ Phone: _____

Name of hospital: _____ Phone: _____

Name of doctor: _____ Phone: _____

Name of doctor: _____ Phone: _____

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Name: _____ Phone: _____

Emergency contact: _____ Phone: _____

Major medical events:

Test or treatment performed	Location of treatment	Date

Other information:

The Missouri Greenbook

Living with Brain Injury

- A guide for survivors, families and caregivers -



"Don't give up. As a survivor for over 10 years,
I experience continual progress every day."

- Andrea Buening, Seneca, Mo.
TBI survivor

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- "Traumatic Brain Injury-Related Hospital Discharges, Results from a 14 State Surveillance System, 1997." Centers for Disease Control and Prevention.
- "Human brain and psychological processes." A.R. Luria. 1966. New York: Harper & Row.
- The Shaken Baby Alliance. www.shakenbaby.com. Online August 22, 2002.
- "What Psychotherapists Should Know about Disability." R. Olkin. 1999. New York: Guilford Press.
- "Acute Brain Injury: A Guide for Family and Friends." Illustrations by James Abel and Loretta Popp. 2004. University of Iowa Center for Disabilities and Development.

Special thanks to the Missourians who have experienced a traumatic brain injury and their family members who contributed their insights to this publication. Their words of wisdom located throughout these pages offer invaluable advice and hope to the thousands of traumatic brain injury survivors and their families across Missouri.

Foreword

You have probably received this publication because you or someone you care about has suffered a traumatic brain injury (TBI). You are not alone.

Approximately 5.3 million Americans currently live with long-term effects of a TBI. More than 14,000 Missourians are admitted to an emergency department or hospitalized each year due to a TBI.

Recovering from a TBI is a lifelong journey. Part of the recovery involves learning as much as possible about TBI. Having information about what has happened and other challenges you may encounter is essential to coping and managing.

The goal of this book is to provide anyone touched by brain injury with information and resources to assist with the journey of recovery. You may personalize the book to you and your needs. Use it to record vital information

about your journey (important tests, procedures, accomplishments). Use it to record questions you may want to ask the next time you visit with a health care professional.

It is normal that you may experience many emotions that come and go at different times throughout your journey. Hopefully, you will find the comments within this book from survivors and family members to be comforting and reassuring.

One of the most significant factors contributing to a survivor's recovery is the level of involvement and support from the survivor's family. Survivors also find great support from other survivors. At some point, they will be reaching out to lend support as well.

A TBI can be a life-altering event, but it doesn't mean that you can't lead a fulfilling and enjoyable life.

"Anyone who has had a family member sustain a TBI has a kinship with others who have dealt with the same issues. We are part of a special family that no one else can really understand."

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor

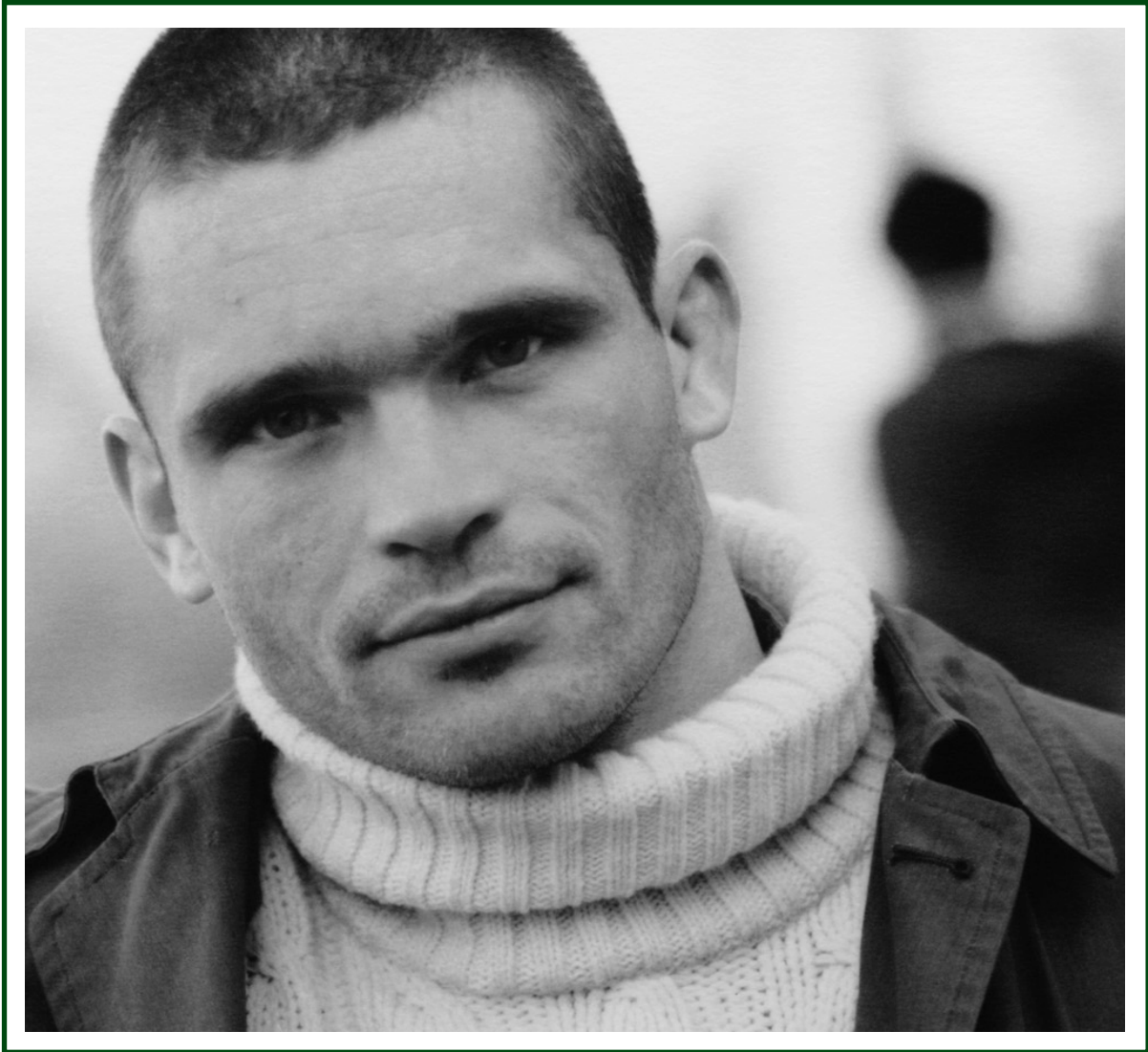
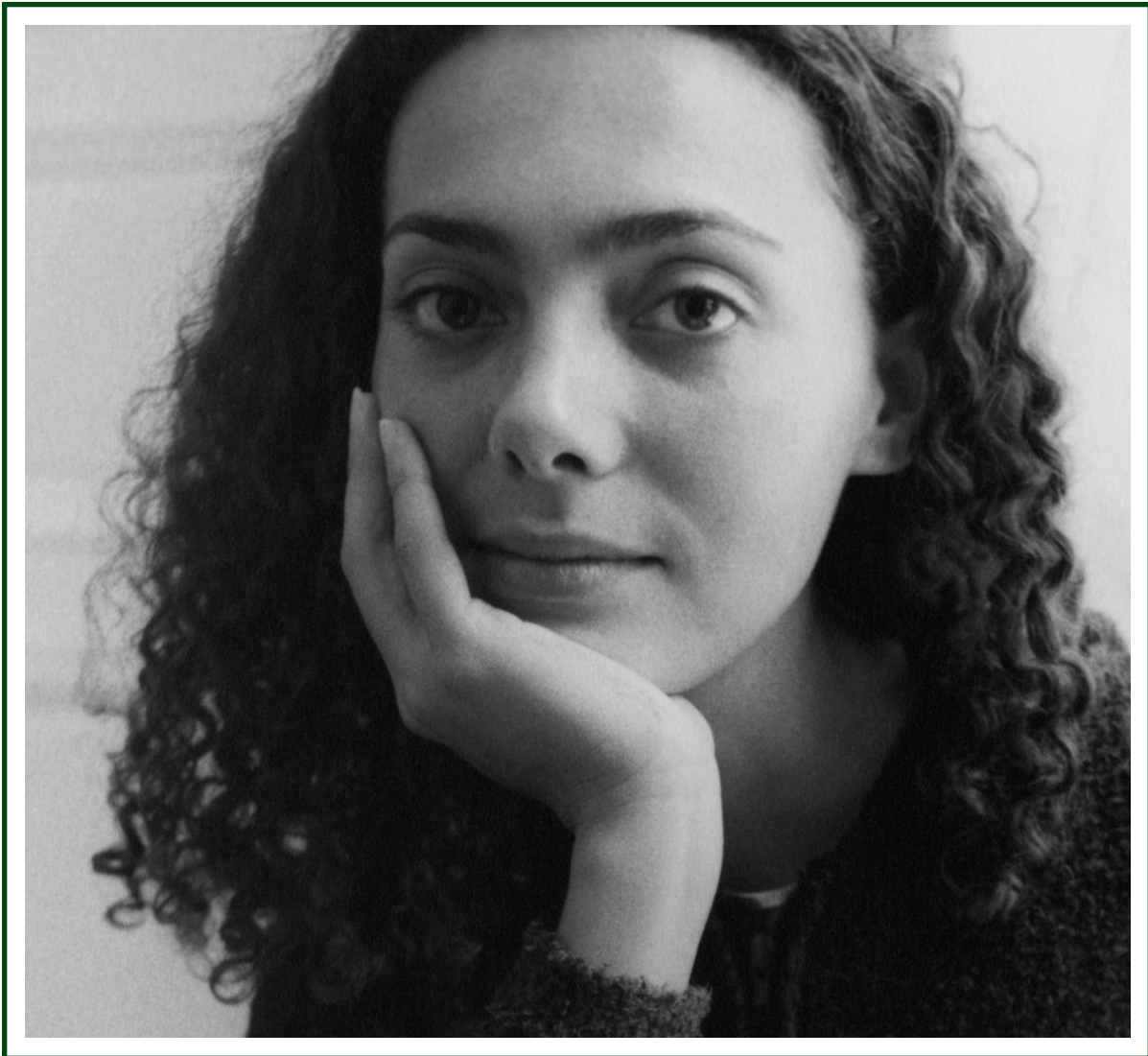


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“Look ahead - do not look back. Do not dwell on the ‘what ifs.’”

- Sue Orton, St. Louis, Mo.
Mother of a TBI survivor



Understanding traumatic brain injury

The brain and how it works

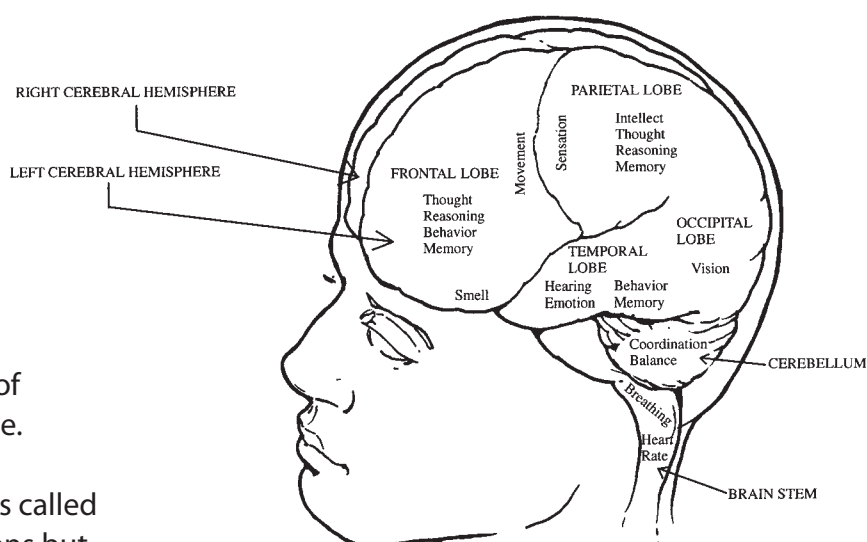
The brain is responsible for everything we do. It controls all movements, sensations, speech, thoughts and emotions. Surprisingly, for such an important structure, the brain is very soft, almost the consistency of firm gelatin.

The brain (Figure 1) would easily be injured if it were not contained by the skull, the bony covering of the brain. The largest part of the brain is made of two halves, the right and left cerebral hemispheres, which fill the top and front of the skull. The right cerebral hemisphere controls the left side of the body, and the left cerebral hemisphere controls the right side of the body and speech in most people.

Within the hemispheres are sections called lobes. Each lobe has special functions but

also works together with the other lobes. The cerebellum, the lower part of the brain located in the back of the skull, controls coordination. The brain stem connects the cerebral hemispheres with the spinal cord and controls basic life-sustaining functions such as heart rate and breathing.

Figure 1



“Learn everything possible about traumatic brain injury. Explore all available sources of information and use what you learn.”

- Arpie Vermillion, Seneca, Mo.
Mother of a TBI survivor

The brain (Figure 2) is surrounded by cerebrospinal fluid (CSF), a clear liquid that is produced by the brain. There are spaces inside the brain, called ventricles, that are filled with CSF. The CSF flows around the brain and down the spine, surrounding the spinal cord and nerve roots all the way to the lower back. The dura is a thin layer of tissue under the skull and bones of the spine that surrounds the brain and spinal cord and contains the CSF.

Traumatic brain injury

A traumatic brain injury is any injury to the brain caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI.

Common causes of TBI are motor vehicle crashes, falls, assaults or blast injuries. The injuries are categorized according to severity as mild, moderate or severe. In most injuries, damage occurs immediately when forces are exerted on the brain. Forces are exerted either directly, as in the case of penetrating or blunt impact, or indirectly as when the brain is subjected to strong forces of movement.

There is a rich network of neural connections linking the brain for rapid transmission and coordinated functions. Injury to the connections can interfere with the brain's ability to function as efficiently as it did prior to the injury.

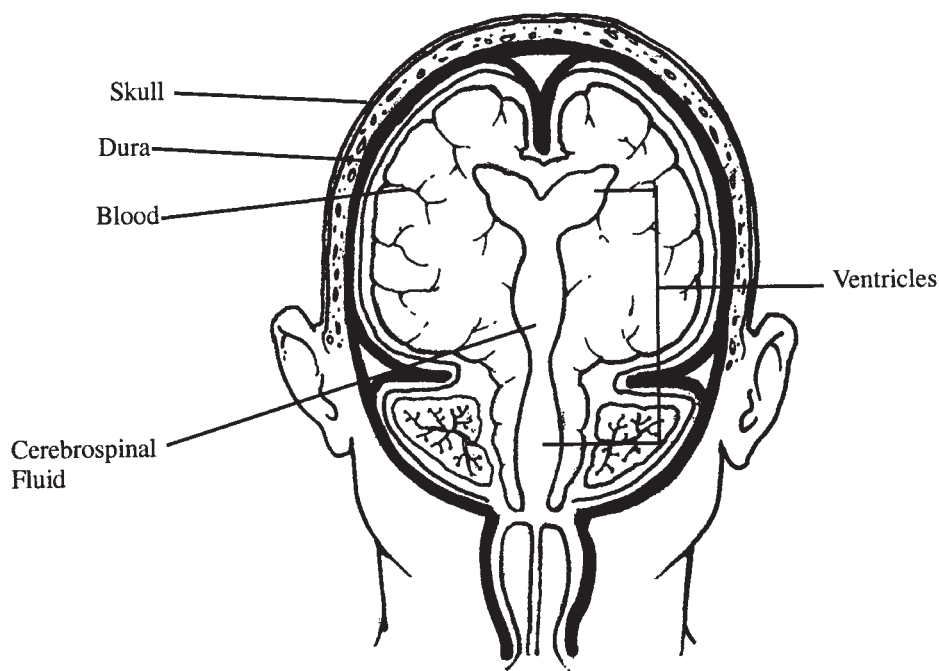


Figure 2

Sometimes bleeding occurs, which results in additional damage to the surrounding brain tissue. In most injuries, the brain responds by swelling. Since the brain is enclosed by the rigid skull, swelling in one area can result in pressure and additional damage to the surrounding areas.

Skull fractures, or breaks in the bone surrounding the brain, may occur with or without damage to the underlying brain. The bone itself will heal over time. Additional treatment may be required if there is damage to the brain beneath the fracture.

Concussion is the mildest form of brain injury. When a person has a concussion he or she may pass out or lose consciousness for a short time, or experience memory loss or loss of other brain functions briefly. Treatment is usually not necessary, however, it is important to observe the patient closely for signs that a more severe injury has occurred.

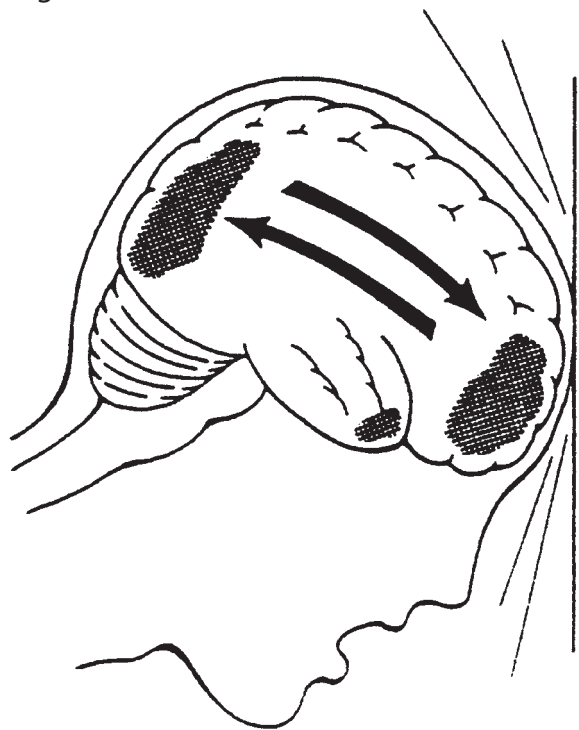
In a **contusion**, a part of the brain is bruised and develops small areas of bleeding and swelling that can be seen on tests. Patients with contusions often complain of headaches, nausea and slow

thinking. Patients with contusions must be watched closely for signs of additional swelling, bleeding or further injury of the brain.

Sometimes opposite sides of the brain are injured when the brain first strikes one side of the skull during the impact and then bounces back against the opposite side of the skull. This is called a **coup contrecoup** injury (Figure 3).

A generalized injury to the brain can occur when stretching or shearing forces are applied to the entire brain. This can result

Figure 3



in damage to the connections, or axons, deep in the brain and is called a **diffuse axonal injury**. In response, swelling can occur throughout the brain. Since the axons cannot be repaired through medical intervention, treatment is directed at preventing further damage. Bleeding in or around the brain is very damaging and is often treated with surgery.

Bleeding that occurs between the skull and the dura, the thin covering over the brain, is called an **epidural hematoma** (Figure 4). If the blood clot is large or increasing in size it is treated with surgery to remove the clot and take the pressure off the brain.

Bleeding also can occur between the dura and the brain. The blood clot forms what is called a **subdural hematoma** (Figure 5). Acute subdural hematomas occur at the time of the injury and are often associated with damage to the underlying brain and severe swelling.

Chronic subdural hematomas occur most commonly in the elderly after a relatively mild head injury. In some cases, a small amount of blood in the subdural space will cause the space to enlarge slowly over time, producing increasing pressure on the brain. In both cases, surgery is often required.

Figure 4

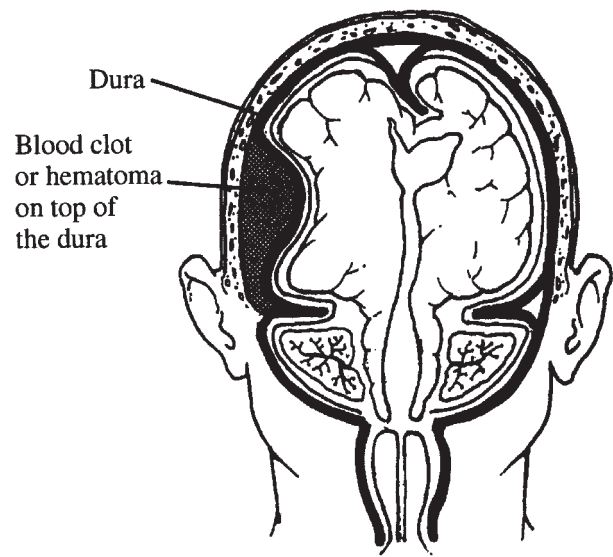
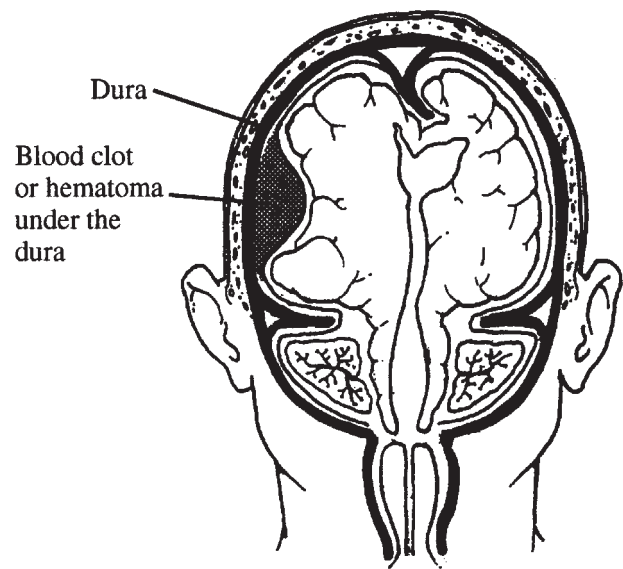


Figure 5



An **intracerebral hemorrhage** is a blood clot within the brain (Figure 6). Surgery may be required to remove the clot, but surgery has significant risks because it may be necessary to go through areas of normal brain to get to the clot and remove it.

Occasionally, bleeding occurs into the spaces filled with CSF. The blood can block the flow of CSF so that pressure builds up in the ventricles, and the ventricles enlarge. This condition is called **hydrocephalus** (Figure 7). Hydrocephalus is often treated with a drainage tube, or ventriculostomy, that drains the fluid to a collection bag outside the body or under the skin into the abdomen.

Any injury to the brain can affect the **intracranial pressure** (ICP), the pressure inside the skull. Since the skull is rigid and cannot stretch, swelling, blood clots or blocked CSF can cause everything inside the skull to become tight and the pressure inside the brain to increase. Much of the treatment of traumatic brain injuries is directed at keeping the intracranial pressure as close to normal as possible.

Figure 6

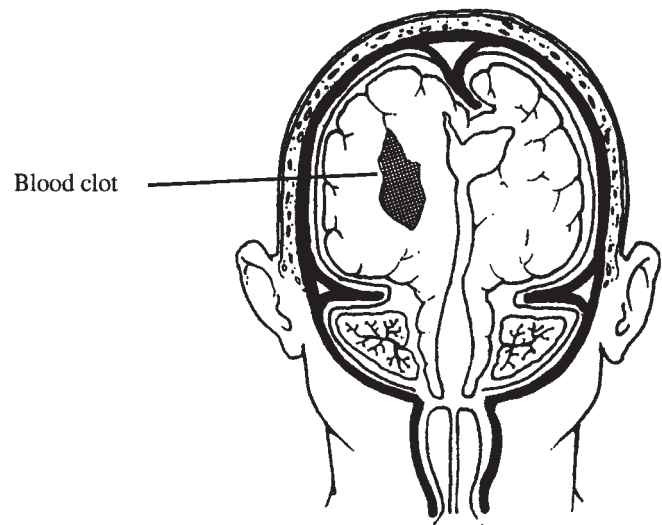
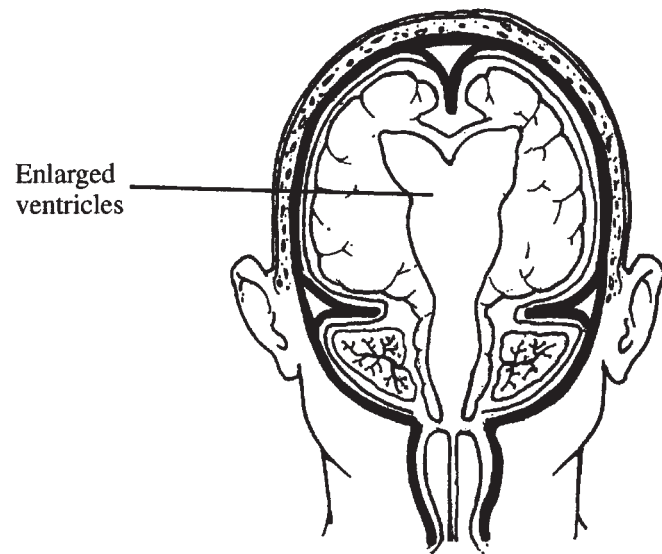
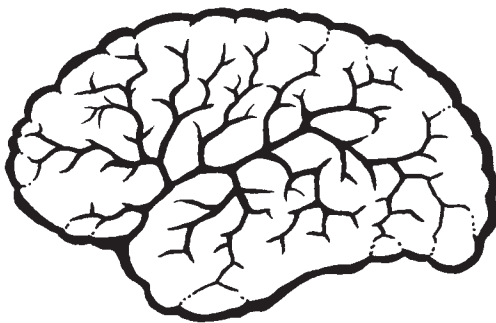


Figure 7

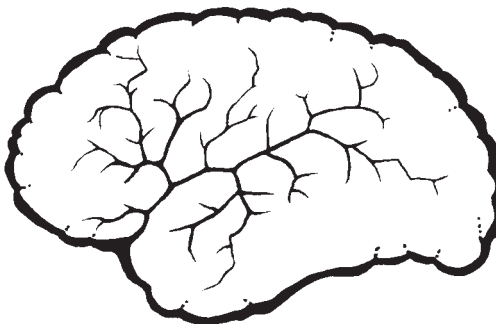


Cerebral perfusion pressure is the pressure that pushes blood into the brain and supplies the brain with oxygen. If the blood pressure is low or the intracranial pressure is high, or both, then the cerebral perfusion pressure will be low, and the blood flow to the brain will decrease. This can cause a low oxygen level and possible damage to the brain (Figure 8).

Figure 8



Normal blood flow



Limited blood flow

Types of TBI

Blows to the head can cause injury to the brain. Sometimes the brain bounces back and forth inside the skull. Other times, objects penetrate the skull and the brain. Both types of injuries are called traumatic brain injuries. A brain tumor or a stroke can result in the same consequences as a TBI but is not a traumatic brain injury.

There are two main types of traumatic brain injury: closed head injury and open head injury. **Closed head injury** (CHI) is caused when the brain is bounced against the skull, often in a back and forth motion, but the skull does not fracture or open.

Some common causes of CHI are:

- Motor vehicle injuries
- Falls
- Bicycle injuries
- Sport injuries
- Blast injuries

CHI may cause problems in a number of areas including:

- Physical
- Cognitive
- Emotional
- Social relationships

The difficulties can even change an individual's personality. Because the injury can affect many places in the brain, CHI is referred to as a diffuse injury.

Open head Injury (OHI) is a visible injury that involves a displaced fracture or penetration of the skull and is less common than CHI. A common cause of OHI is a gun shot wound. An OHI can cause focal (specific) injury at the place of fracture or penetration. In some cases the injury may be more extensive.

Symptoms of TBI

Two signs that indicate the severity of a TBI are:

- Time in coma (not medication induced)
- **Posttraumatic amnesia (PTA)**, the length of time from the injury to the time a person begins to remember things

Impaired consciousness, often called coma, is one symptom of TBI. There are two main ways to measure a person's level of

consciousness: the Glasgow Coma Scale and the Rancho Los Amigos Scale.

The Glasgow Coma Scale, sometimes known as the Glasgow Coma Score, is a neurological scale that aims to give a reliable, objective way of recording the conscious state of a person. The Glasgow Coma Scale assesses a patient's level of consciousness on a scale of 3 to 15.

The Rancho Los Amigos Scale is used to describe cognitive behavior functioning after a TBI on a scale of 1 to 10. The scale provides a way of describing a patient's level of cognitive functioning at a given point in time and is mostly used during rehabilitation.

For more in-depth information about the levels of either scale, ask your health care provider.

Glasgow Coma Scale (GCS)	Rancho Los Amigos Scale
(E) Eye Opening Response (1-4) (M) Best Motor Responses (1-6) (V) Best Verbal Response (1-5) E + M + V = 3 to 15	Level I No Response: Total Assistance Level II Generalized Response: Total Assistance Level III Localized Response: Total Assistance Level IV Confused/Agitated: Maximal Assistance Level V Confused, Inappropriate, Non-agitated: Maximal Assistance Level VI Confused, Appropriate: Moderate Assistance Level VII Automatic, Appropriate: Minimal Assistance for Daily Living Skills Level VIII Purposeful, Appropriate: Stand-by Assistance Level IX Purposeful, Appropriate: Stand-by Assistance on Request Level X Purposeful, Appropriate: Modified Independent

Effects of TBI

It is hard to predict what changes are likely to occur as a result of a TBI. Each individual is unique. The effects of TBI are not always apparent. TBI is often called “the silent epidemic” because thousands of people

“ It is hard to predict what changes are likely to occur as a result of a TBI. Each person is unique. ”

with TBI have symptoms that are not generally evident to others.

The changes experienced after a TBI depend on a number of factors including:

- Pre-injury: educational and vocational history, health history, history of alcohol and substance abuse, intellectual ability
- Injury characteristics: severity of the injury, secondary complications
- Available medical and rehabilitation resources
- Emotional reaction to the injury
- Family and social support

Common problems associated with injury to the brain may include:

- **Motor:** weakness or paralysis of one side of the body (hemiplegia), poor balance and coordination (ataxia), less endurance, abnormal muscle tone and stiffness
- **Perceptual:** hearing, vision, taste, smell, touch, knowing the relationship of the body to fixed objects

- **Speech and language:** difficulty in expressing thought (aphasia), speaking clearly (dysarthria)
- **Executive functioning:** thinking, reasoning, paying attention, judgment, problem-solving
- **Memory and learning:** problems with short-term memory (storing and retrieving recent information), slower learning, limitations in learning, difficulty with retrieval of long-term memory
- **Emotional changes:** moody, easily frustrated, anxious, impatient, angry, depressed and low self-confidence

In addition, a person with a TBI might find changes in basic bodily functions. These include:

- Body temperature control
- Level of alertness
- Swallowing
- Bowel and bladder function
- Sleep patterns
- Endurance for physical and mental activities
- Sexual function

Seizures may occur after a brain injury. They may happen immediately or much later. It is difficult to predict if a survivor will develop seizures.

A diffuse head injury may be mild to severe. It may cause various difficulties with memory, processing speed, attention and reasoning.

A focal injury, on the other hand, affects a specific area of the brain. The difficulties from a focal injury are often more specific and may affect one area such as language or perception.

Following a brain injury, damage to the optic nerve and other parts of the brain can result in a visual blind spot, partial vision loss, or one or more types of visual field deficits.

Visual field deficits after brain injury can be overlooked early on as more severe and life-threatening injuries sustained from the brain injury are treated. People with brain injury should undergo a vision evaluation as soon as possible after injury. Even if problems with vision are not perceived, deficits may be present and can have an extensive impact on life and rehabilitation efforts.

TBI severity

Concussion/mild TBI (MTBI) is defined by an impact to the head that results in minimal to no loss of consciousness, limited posttraumatic amnesia (PTA) and no findings of injury on brain scans.

People with concussion/MTBI might have **postconcussion syndrome** (PCS).

Symptoms include:

- Headache
- Dizziness
- Fatigue

- Diminished concentration
- Memory impairment
- Irritability
- Depression
- Anxiety
- Sleep problems
- Complaints of being physically sick with no apparent reason
- Hypersensitivity to noise and sensitivity to light (photophobia)

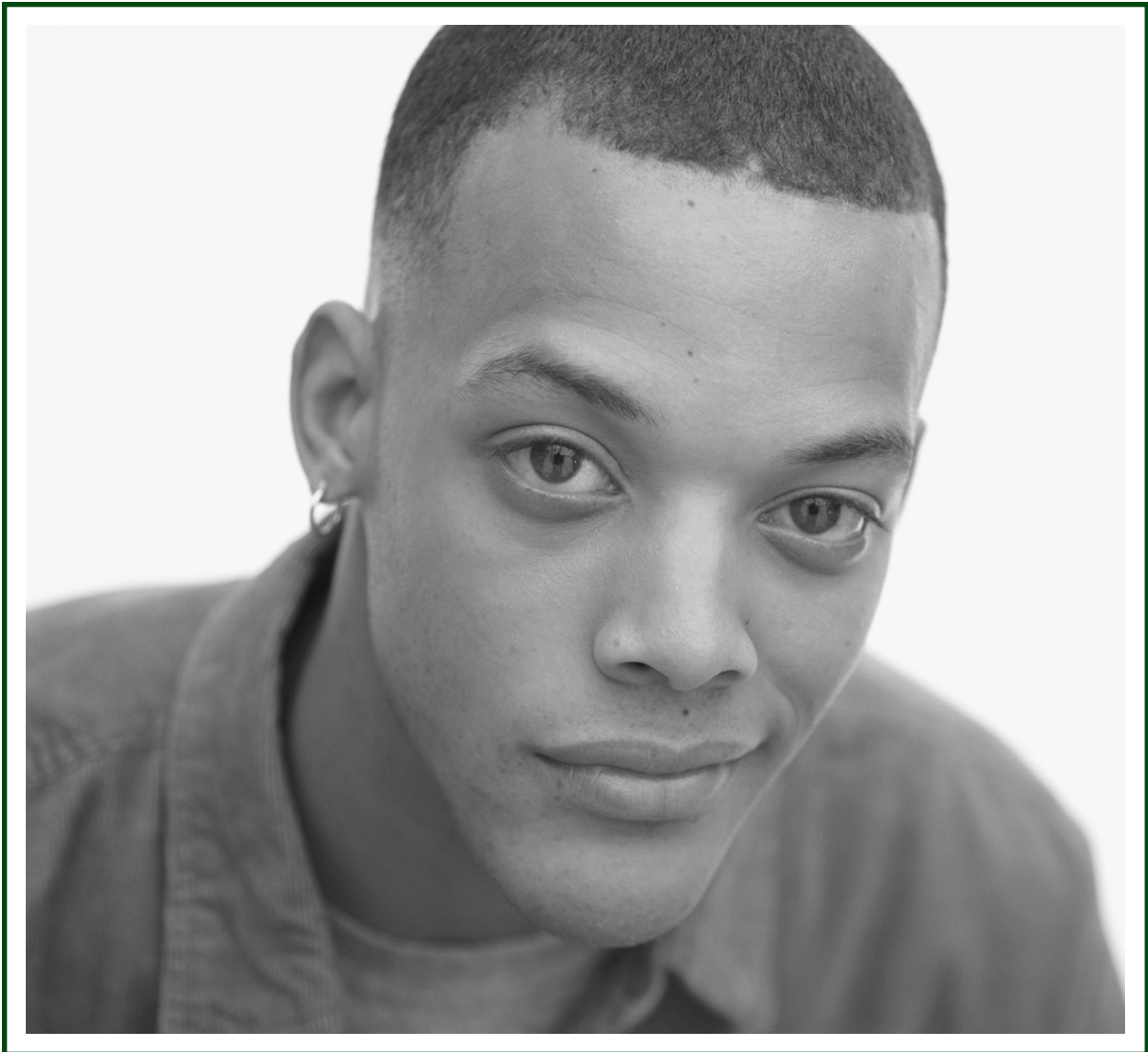
Often PCS symptoms cannot be seen by others. This can lead to loss of self-confidence, frustration, depression and anxiety.

Moderate brain injury may be defined as an injury to the brain resulting in extensive loss of consciousness and PTA as well as some finding of injury on brain scans. Individuals with moderate TBI are likely to experience a higher incidence of cognitive, physical and emotional changes.

Severe TBI may be defined as an injury to the brain resulting in significant loss of consciousness of weeks or longer, PTA extending for days or weeks past emerging from unconsciousness and substantial findings on brain scans evidencing injury across areas of the brain. A person with severe TBI is likely to experience impairments in cognitive, physical, perceptual, social and emotional functioning.

“Be proactive about diagnosis and prognosis. Don’t accept any evaluation as the final word. There is no final word about TBI.”

- Arpie Vermillion, Seneca, Mo.
Mother of a TBI survivor



Treating a new brain injury

Evaluating a TBI

Patients with traumatic brain injuries often undergo extensive testing to determine the extent and location of the damage. A health care provider performs a physical exam specifically including a complete **neurologic exam** which assesses functions of the brain such as strength, sensation, speech, vision and level of consciousness.

X-rays, which show only bony structures, are used to look for fractured bones. **CT** (computerized tomography), also referred to as **CAT** (computerized axial tomography), scans of the brain show soft tissue and are often taken soon after the injury as a way to identify swelling, bruising and bleeding. Occasionally **MRI** (magnetic resonance imaging) scans, which also show soft tissue, may be done to look for subtle damage. An MRI scan may be utilized following a period of recovery as it is helpful in detailing the intricate areas of the brain.

After the initial evaluation, a physician may recommend that an **ICP** (intracranial pressure monitor) be placed. The monitor, which is inserted through a small opening in the skull, allows for continuous monitoring of the pressure in the brain. Treatment decisions are frequently based on the ICP measurements.

Occasionally, it is necessary to measure the electrical activity in the brain with an **EEG** (electrical encephalograph). Wires are attached to the scalp in several locations and brain waves are monitored to look for abnormal activity.

Treating a TBI

The immediate effects of a traumatic brain injury range from a return to normal function after a few minutes to a coma. In a coma, a patient is unresponsive and unaware of their surroundings. All levels of functioning between these two extremes may be seen.

“Learn what levels of care and types of treatment are needed and investigate available options.”

- Arpie Vermillion, Seneca, Mo.
Mother of a TBI survivor

The patient may be confused, disoriented, agitated, or frequently repeat questions or phrases.

When the brain injury is localized to a small area the patient may be normal except for the function affected by the area of the brain that is injured, such as problems with speech or weakness on one side of the body. Whether a loss of function will be permanent or not usually cannot be determined at the time of the initial evaluation.

The goal of treating traumatic brain injuries is to prevent further injury by stopping any active bleeding, keeping the pressure in the brain as close to normal as possible, monitoring blood flow to the brain and preventing any other problems from developing in the rest of the body.

Traumatic brain injury patients are usually positioned so that their head is elevated and neck is kept straight. This position helps control the pressure in their brain.

The fluids that the patient receives are carefully monitored and controlled to decrease swelling. Medications are often used to help control the amount of fluid in the brain. **Anticonvulsants**, or seizure medications, are used to prevent seizures since patients are at higher risk for seizures after a traumatic brain injury. Since movement and stimulation increase the pressure inside the brain, **sedatives** are used to help control the pressure.

Some patients who are not in a coma may appear to be in a coma while receiving medications for sedation. Either the brain injury or the sedating medication

may take away the patient's ability to breathe adequately so a **ventilator**, or artificial breathing machine, may be used. Adjustments of the rate and depth of breaths given by the ventilator can also help to control the pressure in the brain.

Patients with traumatic brain injury are at higher risk for infections, especially if they are not fully awake. Antibiotics may be given in an attempt to prevent infections in the brain or elsewhere in the body. During the course of treatment it is not unusual for patients to develop pneumonia, bladder infections or infection in the blood. Patients may require suctioning, which involves the placement of a small tube into the throat or lungs, to keep the air passages clear and decrease the risk of pneumonia.

TBI patients may need various surgical procedures. Placement of either a pressure monitor or a tube to drain cerebral spinal fluid, a **ventriculostomy**, requires a small opening to be made in the skull. These procedures may be done either in the intensive care unit or in an operating room.

If it is necessary to remove blood, either a small opening called a **burr hole** or a larger opening called a **craniotomy** is made in the skull. Usually the bone taken out is put back in place after the blood has been removed. Sometimes when the pressure in the brain is very high, the piece of bone removed for a craniotomy is left out or placed in a pocket under the skin of the abdomen. This allows more room for swelling in the skull.

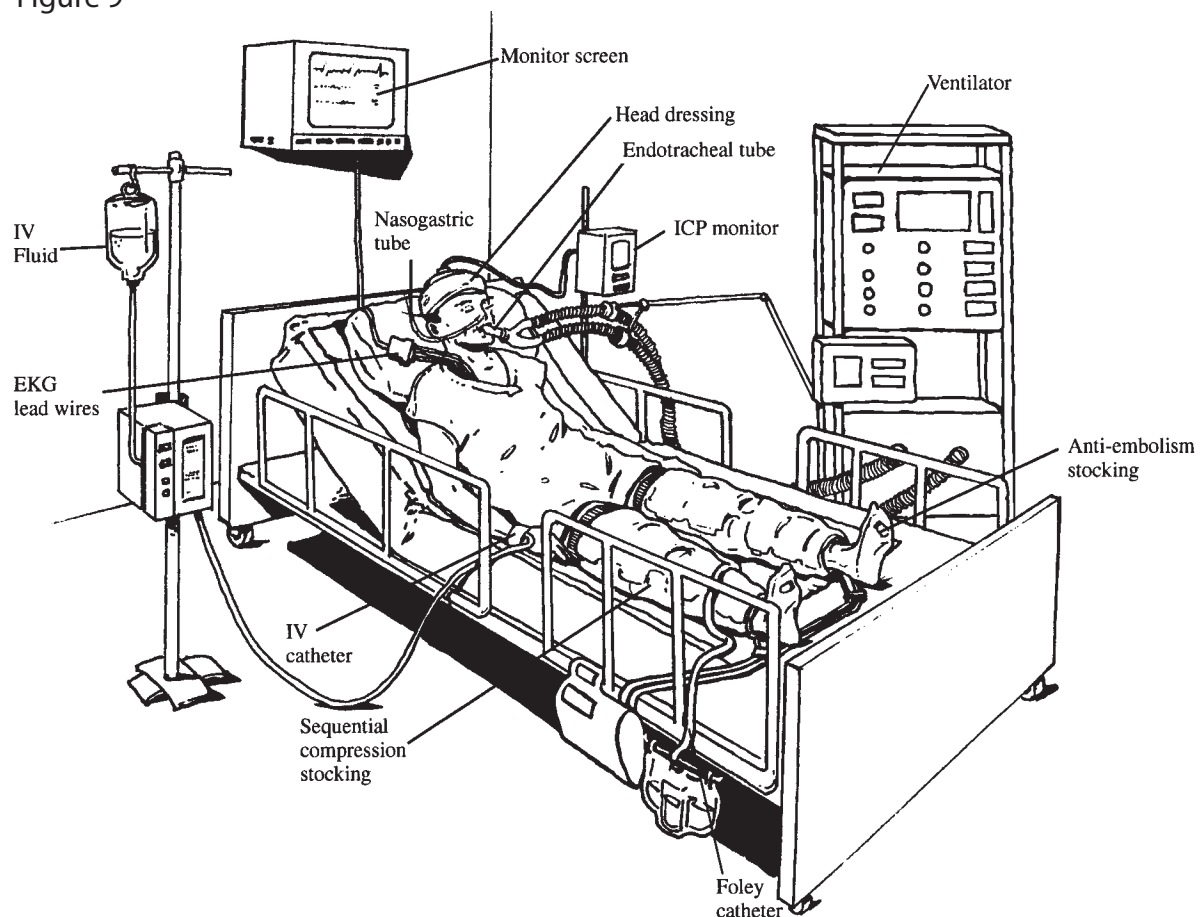
Medical equipment

Various types of equipment may be used in treating TBI patients (Figure 9). That may include:

- **Electrocardiogram (EKG) wires** – Wires placed on the chest to monitor heart rate and rhythm.
- **Endotracheal tube (ET)** – A tube that passes through the patient's nose or mouth into the trachea to help with breathing. The ET tube is usually connected to a ventilator or breathing machine.
- **Intermittent compression boots** – Leg wraps that inflate and deflate to prevent blood clots in the legs.
- **Intravenous catheter (IV)** – A tube placed in a vein so that fluids, nutrition and medicine can be given directly into the bloodstream.
- **Monitor** – An electronic device that constantly tracks various functions including blood pressure, pulse, breathing, and often intracranial pressure.
- **Nasogastric tube (NG)** – A tube that passes through the patient's nose or mouth into the stomach that may be used to pull extra fluids out of the stomach or to put liquid nutrition into the stomach.
- **Urinary catheter (Foley)** – A tube placed in the bladder to allow urine to drain.

If you have any questions about the equipment, ask your physician or any member of your health care team.

Figure 9



The health care team

Many health care providers will be involved in the care of a patient with traumatic brain injury. Usually, a **trauma surgeon** will initially be in charge of coordinating care and treating injuries to the chest, pelvis or abdomen. A **neurosurgeon** may be consulted specifically to take care of the injury to the brain and perform any necessary brain surgery. A **neurologist** may be consulted to treat seizures and any other neurological-based problems.

An **intensivist** or **pulmonologist** may help manage problems with breathing, blood pressure or intracranial pressure. Orthopedic surgeons, infectious disease specialists, thoracic surgeons or other specialists may be consulted if the need arises.

A **physiatrist**, a physician who specializes in physical medicine and rehabilitation (PM&R), may become involved early in the care of the patient to coordinate physical rehabilitation services.

Physical therapists work on motion, strength and coordination. **Occupational therapists** try to restore the patient's ability to perform **activities of daily living** (ADL) such as eating, dressing and grooming.

Physical therapists, occupational therapists, and speech pathologists will become involved as the patient stabilizes and begins to recover. Therapy is aimed at helping the patient regain function or become accustomed to changes in function.

Speech pathologists direct their therapy to improving speech, swallowing and thought processes.

Dietitians will assess the nutritional needs of the patient and determine the best way to meet those needs. In severely injured patients, nutrition may first be given into a vein, progressing eventually to a normal diet of solid food, depending on the level of recovery achieved.

Respiratory therapists monitor breathing, secretions from the lungs and the level

“ Many health care providers will be involved in the care of patients with traumatic brain injury. ”

of oxygen in the blood. They may give breathing treatments, suction secretions or adjust oxygen levels as needed.

Recovery process

It is often difficult for health care professionals to answer a family's questions about whether their loved one will recover completely and how long the process will take. Most treating physicians and rehabilitation team members will talk in generalities especially during the first six months, which is a very dynamic period of recovery.

Families and individuals with TBI can find themselves feeling frustrated and concerned when recovery takes longer than expected and the person is changed. This is a typical reaction as the individual and family members are anxious to return

to previous life activities. The following information provides general information gleaned from research on outcome following TBI:

- The majority of individuals experiencing concussion/mild TBI recover fully within about three months.
- Six out of 10 people with TBI have mild or no permanent significant disability. They may experience mild changes in thinking or emotional adjustment that can interfere with their school, work and/or family life.
- About three out of 10 people with TBI have lifelong moderate disability. They can continue to have productive lives even though they have ongoing problems.
- The recovery process for moderate to severe brain injury typically occurs within the first one to two years after the TBI. However, research suggests that ongoing improvement in compensation and function, to a lesser degree, can occur after two years, and mostly among individuals who continue to work on areas of change.
- The length of stay in an inpatient rehabilitation unit varies with the level of injury although statistics

show a typical range from three to 12 weeks.

- The length of care in outpatient rehabilitation is often dependent upon payer limits and may also last for weeks to months at decreasing levels of treatment frequency.
- About one out of every 10 people with TBI has severe disability and needs long-term care.
- Less than one percent (0.6 percent) of individuals with TBI remain in a coma for a long time or rely on machines to live.

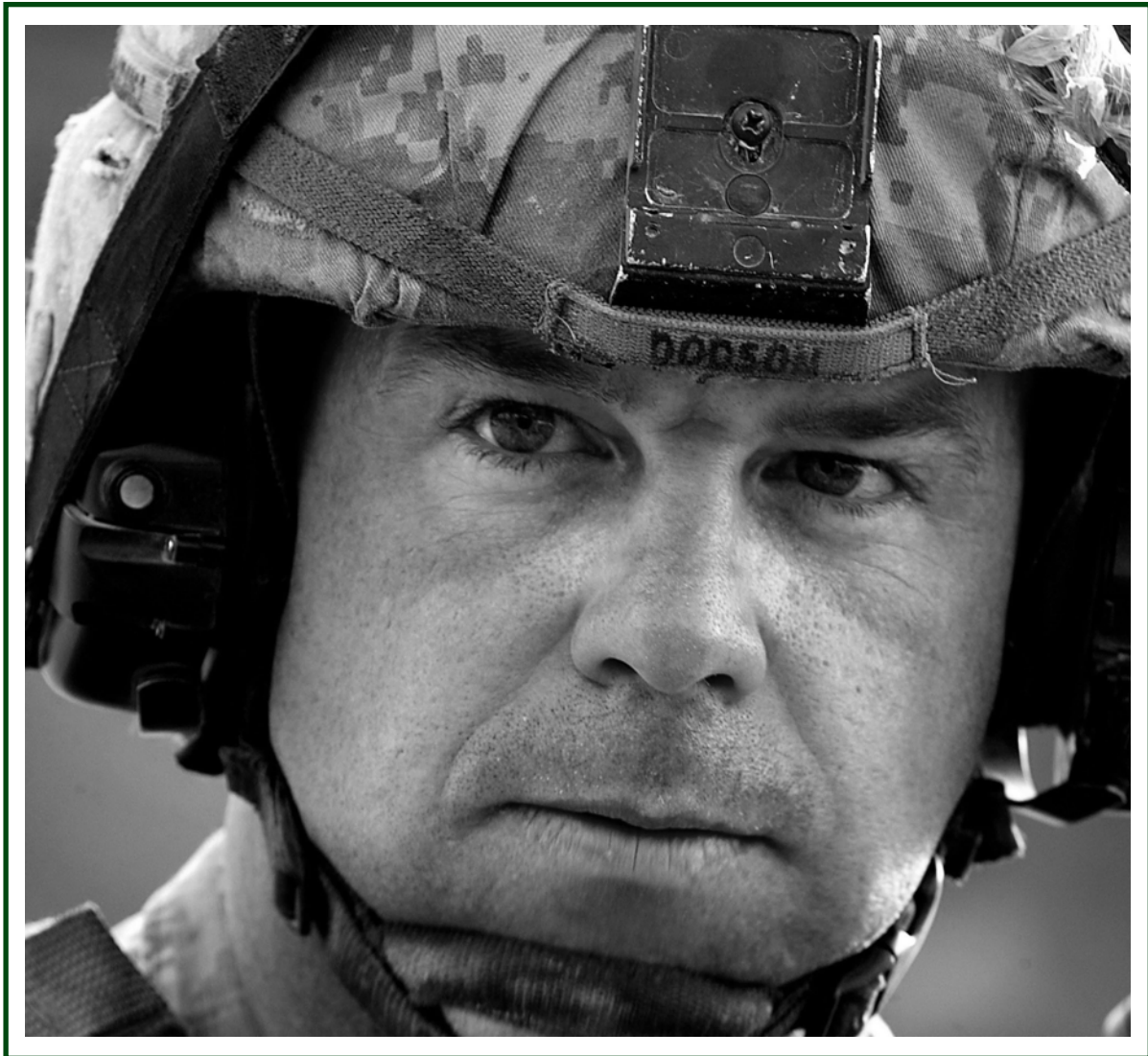
Making the most of the hospital stay

Families of patients with traumatic brain injuries are often overwhelmed by the amount of personnel, procedures and equipment required for treatment. It is helpful to keep a journal of events occurring throughout treatment and recovery.

Keeping a list of questions for health care providers can keep communication open and avoid confusion and unnecessary stress. Many families establish a phone tree or use the Internet to transmit important information to family and friends in a way that is less time consuming and burdensome. If the hospital stay and recovery are prolonged, which is common, a rotating schedule of visits will provide respite and comfort to all involved.

“Keep a positive attitude even through your tears. Never lose hope.”

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor



Rehabilitation

Medical rehabilitation

The principal goal of medical rehabilitation is to promote physical recovery and help the individual with TBI to relearn or strengthen skills necessary to care for themselves and return to a productive, independent life. It is often an extensive process. It can begin as soon as the person with TBI reaches a level of medical stability.

Rehabilitation addresses problems related to:

- Motor skills related to use of one's hands, legs and body
- Sensory-motor areas including balance, swallowing, vision and sensory perception
- Memory and new learning
- Executive functions of reasoning, judgment, awareness and attention
- Information processing speed
- Language and communication skills
- Emotional adjustment and stability
- Organizational skills

- Social skills and interactions
- Restoring sleep and eating patterns

Medical rehabilitation begins with developing a treatment program through the input of the individual with TBI, their family/support system and the rehabilitation team, which may include:

- Neuropsychologist/rehabilitation psychologist
- Speech and language therapist
- Physical therapist
- Occupational therapist
- Rehabilitation nurse
- Social worker
- Special educator
- Recreational therapist
- Vocational rehabilitation counselor
- Physician, physiatrist
- Case manager
- Chaplain and/or counselor
- Specialty care: vision therapy, vestibular therapy, alcohol/substance abuse counseling, specialty medical services

“Be present, be available, be flexible, and put into practice what you have learned.”

- Arpie Vermillion, Seneca, Mo.
Mother of a TBI survivor

Medical rehabilitation services may begin in the intensive care unit (ICU). However, inpatient rehabilitation services are generally provided in a:

- Hospital rehabilitation unit
- Rehabilitation hospital or center
- Skilled nursing unit

Criteria for admission to an inpatient medical rehabilitation unit/hospital is based on the severity of injury and need for intensive physical and nursing care as well as the patient's ability to tolerate three hours a day of intensive medical rehabilitation therapies.

An individual who is not in need of substantial medical care but cannot yet tolerate intensive medical rehabilitation may be transferred to a skilled nursing facility. Additionally, factors associated with medical care needs, dependency on others for general activities of daily living and the availability of an appropriate caregiver may suggest placement in a skilled nursing unit until further recovery occurs toward greater independence or it is determined that the individual requires long-term substantial nursing care.

This setting provides nursing and medical care as well as medical rehabilitation therapies at a reduced level of intensity. Upon further recovery, the individual may progress to being transferred to a medical rehabilitation unit for intensive therapy.

A TBI patient is likely to be discharged from the medical rehabilitation unit when medically stable and no longer in need of nursing care. It is quite common for

the individual to have continued need for rehabilitation and assistance in the home for daily activities. Efforts are made to discharge the person to their home with plans for continued rehabilitation as an outpatient.

Criteria for admission to an outpatient medical rehabilitation program is dependent upon the range of services. Day hospital programs often offer nursing care, providing for individuals who continue to require a higher degree of help with self care, medication administration and general supervision. A day hospital program may include day-long therapies with established rest breaks throughout the day.

Specialized TBI day treatment programs are geared for individuals who are independent in self care and are ready to engage in therapies with a community reentry focus (home care, vocational planning, recreational therapy). Many comprehensive medical rehabilitation programs often include neuropsychology/rehabilitation psychology services to assist with treatment planning and adjustment.

Traditional outpatient programs offer occupational, physical and speech therapy. Such programs often require that individuals either be entirely independent in self care or have a caregiver with them who can provide care if it is needed while the person is in therapy.

There will come a point during which the patient has reached a leveling of progress when limited documented gains are noted

over a period of time. It is at this point that the person is likely to be discharged from outpatient medical rehabilitation and transitioned to a home program of exercises and activities to facilitate additional recovery.

The individual and family may feel a degree of anxiety and concern at the conclusion of formal intensive therapy. Many report a sense of concern that they will not continue to improve outside of formal therapy. The rehabilitation team strives to prepare the individual and family for the next step in recovery, which includes home programs and vocational/educational plans and activities.

Planning for rehabilitation

At certain points, an individual may profit from additional rehabilitation services to promote recovery, strengthen an area of decline since the injury or treat a new problem associated with the original injury. Individuals with TBI and their family/support system are encouraged to advocate for the needs of the individual across their life span.

The rehabilitation team typically holds regular meetings to discuss the progress made and modify the treatment plan to meet the person's current needs.

The rehabilitation team will regularly meet with the patient and designated family members to develop and refine the treatment plan, discuss any changes in the plan and provide updates on progress.

Developing an overall rehabilitation plan may include choosing an appropriate rehabilitation provider (inpatient or outpatient), skilled nursing facility or in-home care. It is important to:

- Promote rehabilitation early in the treatment process and seek information about the rehabilitation treatment plan throughout the individual's inpatient hospital stay.
- Understand the level of recovery and care needs of the person with TBI (need for help with daily activities, medical care needs, needs for supervision, special accommodations needed for safety).



- If an inpatient or outpatient rehabilitation service is recommended, identify local and regional TBI rehabilitation programs or skilled

the individual to need help with self-care (dressing, bathing, toileting, eating) and to need a level of available supervision to provide care and safety. Early

planning and assisting the family with making necessary arrangements will substantially decrease the stress and frustration that can occur when family resources are further strained.

Finally, it is quite likely that the individual will be discharged home and/

or discharged from medical rehabilitation services well before one-year post injury. However, the recovery and healing process continues. It is vital to develop a home program to facilitate recovery and improve functional strength and capacity in physical functions, perceptual functions, cognition and emotional adjustment. Valuable resources for developing a home plan include the rehabilitation team, state brain injury resources and support services through the Brain Injury Association.

Some individuals go to live in residential care facilities such as independent living centers and long-term care facilities. A discharge plan explores various residential options and helps the person and their family select an option that meets the needs of the individual.

Living well with TBI

The long-term goal of rehabilitation is to return to community participation, engage in meaningful life activities and develop skills in self-direction. Significant changes may not allow a person who has experienced a TBI to return to all previous life activities, which often creates a feeling

“...begin making plans for discharge home from the beginning of the treatment process.”

nursing facilities and tour viable options.

- Obtain specific information about available rehabilitation benefits through commercial insurance, state Medicaid programs and community resources.
- Speak with a social worker, bank or legal counsel to learn how to temporarily manage the patient’s financial affairs (if the patient is an adult). If the individual has significant care needs and lacks capacity to make major decisions, you may want to seek legal advice regarding guardianship.

Returning home

It is important to begin making plans for discharge to the home from the beginning of the treatment process. It is helpful to quickly identify likely necessary home modifications for returning home after hospitalization. The social worker or case manager may provide useful information about resources to complete modifications.

The individual with a moderate to severe TBI is likely to have care needs impacting the family. At least initially, it is typical for

of loss for the individual and the family. Holding on to the past can interfere with moving forward and being satisfied with life choices.

Experts recommend:

- Adopting a problem-solving strategy that seeks realistic solutions to current challenges.
- Setting and pursuing short range and long range goals.
- Finding a helpful mentor for thinking through decisions and plans.
- Educating yourself on your strengths and areas of challenge.
- Keeping a diary or journal of medical events, treatment providers, resources, medications and pertinent personal information.
- Knowing and using available resources as needs require.
- Keeping a hopeful and positive mindset about what the day and future can hold.
- Remembering you are not alone, there is support available and that your family has endured a difficult experience as well.
- Seeking support from professionals and families with similar experiences.

Family role

A major goal for the family is to serve as an encourager and facilitator. Families should remember that adults appreciate their independence. Families can help by:

- Understanding the individual's strengths and challenges.
- Encouraging and helping the individual, if necessary, keep a diary or journal.
- Assist with problem-solving in developing options for solving challenges.
- Helping identify community, state and federal resources and be willing to participate in exploring resources.
- Seeking assistance for personal issues you may encounter with your own adjustment to the injury experience. Brain injury affects the entire family.
- Staying positive, focused and solution oriented. It rarely helps to be argumentative or forceful even if your loved one is struggling to come to a decision.

Service coordination

Service coordination services may be available through some state programs.

A service coordinator can:

- Provide information for all individuals about useful resources for living with TBI and returning to life activities in the community.
- Help the individual with a TBI obtain services and resources needed to meet needs and goals.

Refer to the Resources section of this book for more information on service coordination.

“You have to be the advocate since someone with a TBI often can’t advocate for themselves. You and your family will live with the outcomes, not the physicians, politicians, nurses, therapists and teachers. Stay informed and educate yourself.”

- Sue Orton, St. Louis, Mo.
Mother of a TBI survivor

Service definitions

Once at home and returning to community activities, an individual may need ongoing services. Some of the services may only be needed for a specific amount of time.

The following are some services an individual or family may need, along with an explanation of each:

Service coordination/case management – assistance for individuals and their families to find and obtain the services and resources that they want and need

Personal care assistance – in-home assistance that may include help with dressing, bathing, eating or other personal care activities

Occupational therapy – activities to work on fine motor skills, perceptual skills, eye-hand coordination and self-care skills

Physical therapy – activities to work on motor functioning, muscle tone, movement, balance, endurance, ability to ambulate, strength and coordination

Speech/language therapy – activities to help with swallowing, speech, communication, listening, conversation and higher-level cognitive skills

Vision therapy – specialized vision therapy to promote skills in ambulation and community integration

Driving evaluation and training – assessment of safety and skill in returning to driving a personal vehicle; may include specialized training and recommendations for adaptive equipment in the vehicle

Neuropsychology – comprehensive assessment of cognitive and emotional functioning to help with treatment planning, community integration, educational and vocational planning and identifying needed supports and services

Rehabilitation psychology – assistance with adjustment for individuals with TBI and their family/support network; develop behavior plan for challenging behaviors

Psychiatry – medical management of emotional dyscontrol or poor behavior control when behaviors significantly interfere with the individual's successful participation in home and community activities

Special education and related services – identification of the need for an individual education plan (IEP) or 504 plan to provide appropriate accommodations and special education and therapy services for children and adolescents returning to school; involves identifying school based pre-vocational and vocational services (for people under age 21 who have not yet graduated from the public schools) and identifying available resources and accommodations provided in secondary education centers and vocational training programs

Pre-vocational/pre-employment training – a range of activities that may include practicing work-like activities, working on resumes and job interviewing skills, strengthening worker skills, and helping a person prepare for future employment

Supported employment – provides support needed to perform job tasks; includes job coaching, individualized job skill training, developing work behavior plans and other support services while on a job

Sheltered workshop employment – noncompetitive employment in a structured and supervised safe environment for persons with disabilities who are unable to be employed competitively or in a supported work setting

Transitional home and community support training – assistance in learning skills and strategies to successfully and independently manage roles and responsibilities for daily living and household operations

Supervised living arrangement – a residence in the community that substitutes for the individual's own home or for the home of the individual's family

Long-term nursing care – residential programs that accept individuals once they are medically stable and may provide rehabilitation services in addition to nursing care

Respite care – temporary or emergency care relief for the caregiver

Supported housing – support necessary to live successfully in a chosen environment (such as paying bills, shopping, etc.)

Vocational rehabilitation – work evaluation and adjustment, job training and job placement

Some of these services may be provided through state and federal programs. See the Resource section of this book for contact information.





Life after rehabilitation: home, work and school

This section offers a number of suggestions that can help individuals with TBI move forward after formal rehabilitation ends and gradually resume their daily activities.

Being home

- Work with your family to divide duties, including breaking jobs into smaller tasks that you can manage safely.
- Develop a schedule and routine that includes participating in home-care activities every day.
- Set a routine and schedule for self-care activities.
- Identify any home modifications or adaptive equipment that might be helpful in your ability to participate or complete tasks.
- Regularly talk with family about your progress on tasks and increase participation over time.
- Recognize that tasks may take more time and energy and allow ample time for completion. At least initially, periodic brief rest breaks may be useful.
- Modify the environment to be quieter or slower paced when you are working on tasks. This will help prevent you from becoming overstimulated by noise and activity.
- Keep a family calendar for tracking important dates. Get a large calendar with room for recording daily events that may be important to recall later.
- Keep paper and pens by all phones and develop the habit of keeping notes of calls.
- Keep an organized house so that frequently-needed items have a set place.
- Declutter work areas and avoid visual overstimulation.
- At the beginning of the week, meet with family to plan for the upcoming week.

“Allow people the blessings of helping you. You can’t do it alone. Tell them what you really need when they ask.”

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor

- Begin every day by reviewing the calendar and planning the use of your time to complete the day's tasks.
- Build in time for social interaction daily.
- Incorporate physical exercise into each day.
- Make reading an important part of every day. Also, participate in intellectually stimulating activities that may include puzzles, crafts, games and mental challenges.

Attending college or vocational training

- Your first task should be to speak with staff in the student services office about available accommodations and services for students with disabilities.
- Choose a school/program that offers smaller class size and easy access to instructors.
- Begin with a conservative (part-time) course load. Use the first semester to focus on school success.
- When scheduling courses, try to achieve a balance between intense classes and less demanding classes.
- Include classes of great interest to you even if at a pass/fail level.
- Speak with instructors individually to let them know of your learning needs and establish a plan to address your needs. Make sure the instructor has a copy of any accommodation plan prepared by the student services office.
- Always sit close to the instructor or other learning source to avoid distractions.

- Plan to tape record lectures for possible later review as needed to enhance learning.
- Determine the need for a note taker. You may want to exchange notes with a peer.
- Use tutorial labs frequently to review material and reinforce learning.
- Establish a quiet study environment and a set a daily study period.
- Monitor grades routinely and meet with your instructor immediately for assistance if you receive a poor grade.
- Carry a planner/calendar to class and record upcoming assignments and tests. Break down assignments to indicate when you plan to study and complete all or parts of the task.
- Schedule plenty of rest breaks into your day.

Driving

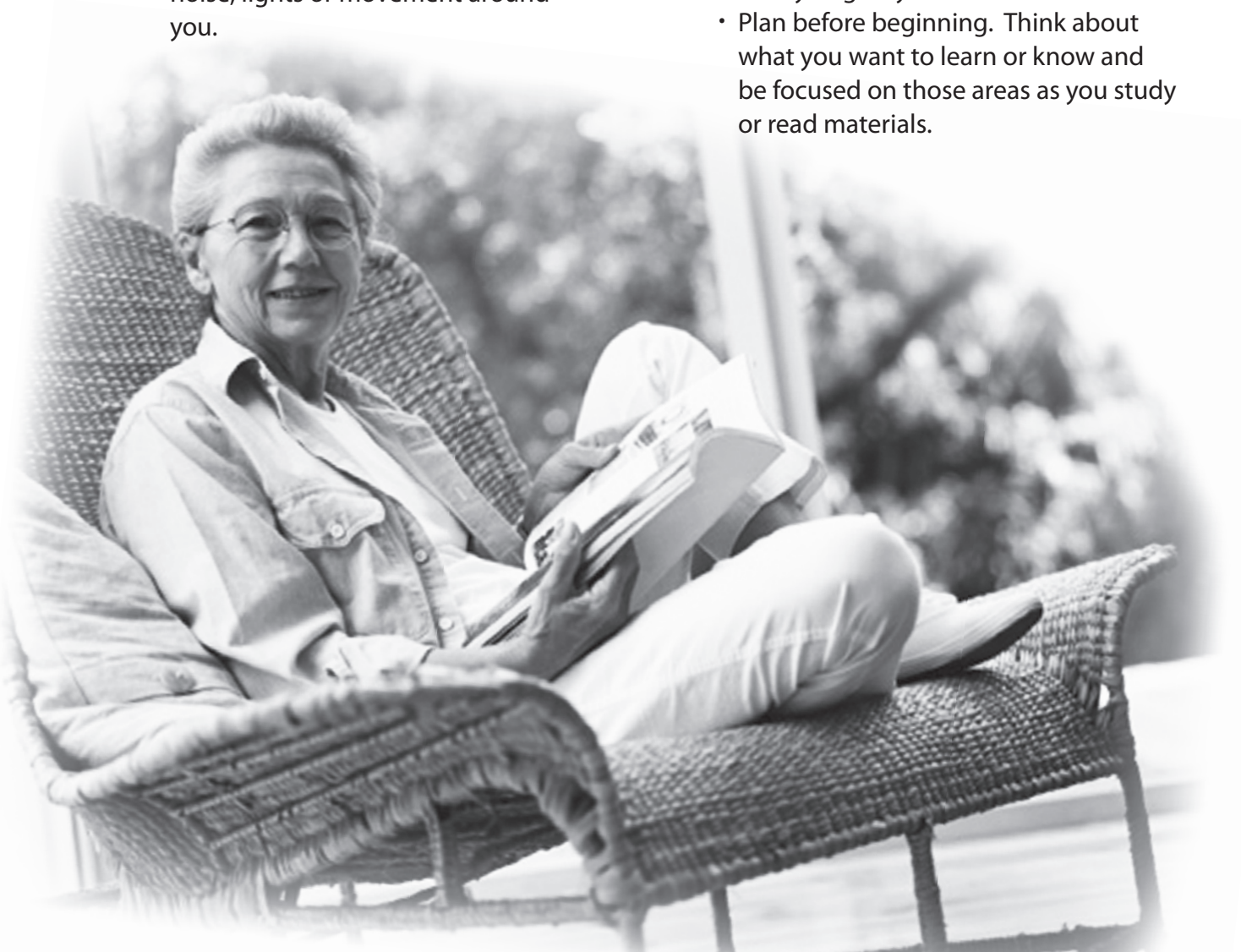
- Speak with your treating physician about your readiness to complete a driving evaluation.
- Once released to complete an evaluation, explore available driving evaluation programs with expertise in TBI.
- Do not return to driving unless released to do so by your treating physician.
- Upon release to return to driving, make appropriate modifications to your vehicle and change your driving habits to ensure the safety of yourself and others.
- When returning to driving, avoid heavily congested traffic areas and time periods.

- Keep distractions out of your car when driving. Don't use a cell phone when driving or engage in distracting social behaviors.
- Recognize fatigue and do not drive when tired.
- Address any visual limitations related to driving.
- Never use alcohol or illicit chemicals and drive.
- Always wear a seat belt in the vehicle.

Attention

- Avoid distractions that may include noise, lights or movement around you.

- When taking notes, repeat back what you have written to ensure that you have all of the details.
- Use a highlighter marker to draw attention to specific areas on a page.
- Study or read in a quiet environment.
- Look directly at people during a conversation.
- When studying, take notes on what you are reading.
- Be an interactive listener by periodically rephrasing what the other person is saying during a conversation.
- Avoid multi-tasking, which taxes your ability to give your full focus to tasks.
- Plan before beginning. Think about what you want to learn or know and be focused on those areas as you study or read materials.



- Avoid unnecessary visual clutter that may affect your ability to find things.
- Develop a system for having necessary items always placed in set places.
- Use large and colorful labels to organize and mark materials to make them easier to locate.
- Turn down or turn off the TV or radio when trying to talk on the phone or have a conversation with others.
- In restaurants, ask for a table in a quieter area and seat yourself in a place where you are less distracted.
- Ask people to speak up and be clear when talking to you.
- Ask people to cue you when you do not appear to be giving your full attention.
- When studying or reading, take brief breaks about every 15 to 20 minutes then immediately return to your work, review and proceed.
- In your wallet or purse, carry a list of your medications, medical conditions and emergency contact information.
- Repeat back what you are told and write it down to ensure that you have all the details.
- Develop a routine for regular activities including taking medications, home tasks and self-care.
- Keep a central calendar in your home and write down all appointments and upcoming events.

“ Develop memory strategies that help you learn new things. ”

Memory

- It is imperative that you learn to carry pencil and paper for keeping notes. Use a small notebook, calendar or single piece of paper for note taking.
- Consider carrying a small tape recorder for taping notes for yourself.
- Call your voice mail and leave notes and reminders for yourself.
- When you go to the doctor, always take your calendar and diary/journal of your injury, medical history and current medications.
- Begin the week and day by reviewing upcoming activities and planning your time accordingly.
- Ask for call reminders of appointments.
- Keep sticky notes available for quick notes. Remember to frequently review sticky notes to remind you of a task that is undone. Get rid of notes that are no longer current.
- Make a daily “to-do” list. Then make a note next to the item for when you will complete the task. Review your list at the end of the day and decide which tasks need to be carried over into the next day.
- Allow extra time for new learning.
- You will likely need to practice new learning to maintain the information.
- Understand your preferred learning mode. Some people learn better

by reading or hearing whereas others learn better by watching, seeing and doing. Use your preferred mode for new learning.

- Avoid distractions and interruptions that interfere with your ability to encode information into memory.
- Use cues to trigger memory. A cue is something that will remind you and help your brain know where to find the information.
- Take responsibility for your memory rather than expecting family and friends to be your memory for you. You will remember more easily if it is important to you.
- Develop memory strategies that help you learn new things: turn a list into song; make a mental picture; develop a word cue for an idea.
- Pair a learned activity with a new task that needs to be part of your routine. For example, pair taking a medication with brushing your teeth in the morning.
- Use a weekly medication tray to help keep track of medications.
- Keep a medication log and check off when each dose is taken.
- Use timers in your house to cue you of an upcoming task that you need to do.
- Use the alarm on your watch to cue you.
- At night, prepare everything you need to take with you the next day and place it all together.

- Accept that remembering things may be more challenging and ask others for assistance with new learning or reminders.
- Develop specific strategies for your needs with the help of family, a speech pathologist, or neuropsychologist or rehabilitation psychologist.

Judgment

- Find a mentor to help you think through important decisions.
- Use a decision making strategy that includes:
 - Collecting all important data
 - Determining potential solutions
 - Assessing how realistic each option is
 - Examining the pros and cons of each decision
 - Thinking through possible consequences to you and others
- Take your time in making decisions and avoid acting impulsively.
- If you make a mistake, review your decision-making strategy and learn from your mistakes. Also, figure out a way to correct mistakes.
- It is typically very useful to talk out decision-making because it will help you understand how you feel and think about a situation.
- Decisions are best made when you are calm and not when you are distressed or angry.

“It is important for families to remember that when their survivor seems to be different they are not the same person they once were. The original person may peek out from time to time, but TBI can cause a great change.”

- Andrea Buening, Seneca, Mo.
TBI survivor

- Keep good friends who are willing to be honest and supportive. Good counsel leads to better decisions.
- Lean toward decisions where you are the main person responsible.
- Practice empathy, putting yourself in someone's shoes and thinking about how they would feel.
- Think first before talking or acting.
- Think about your comments or actions. Ask yourself:
 - How will the other person feel?
 - How will the other person react?
 - Is this how you want to behave?
 - Will this obtain the desired effect?
 - Are you willing to accept the consequences?
- Behave and make decisions consistent with your value system.

Processing speed

- Allow enough time to complete tasks.
- Think about how much time will be needed to complete a task before beginning.
- Learn to slow down the flow of information so that you do not feel overwhelmed.
- Tell people to slow down if they are talking or moving too fast.
- Look for work settings that match your preferred work pace.
- Keep track of how long it is taking to do a task. This will help you readjust your internal sense of time.
- Choose times to go to the store or office when the staff is likely to have extra time and not rush you.
- If you drive, choose times and routes that are less busy or rushed. Leave

early to allow extra time to get to your destination.

- Talk to your doctor about safety using power equipment (lawn mower, all-terrain vehicle, power tools, etc.).
- Help your family understand your need for time so that you and they do not feel as rushed completing routine tasks such as getting ready to leave or completing daily chores.

Your health

We all function better when we take care of our health. TBI may create specific health issues, and you are encouraged to work closely with your physician to manage any chronic health conditions. Some general health recommendations include:

- Have annual examinations.
- Comply with medication recommendations (take only as prescribed). Do not discontinue a medication without discussing the decision and process with the doctor prescribing the medication.
- Tell your doctor about all of the prescription medications that you are taking and your use of over-the-counter medications (ibuprofen, acetaminophen, etc.), and vitamins and supplements. Your doctor needs to know about possible interaction effects in order to provide good care.
- Tell your doctor if you are using alcohol, street chemicals (such as marijuana or cocaine) or tobacco. These substances affect your overall health and the effectiveness of your

medication.

- Have recommended preventative procedures (annual PAP, mammogram, colonoscopy, prostate exam, etc.).
- Have annual eye exams and annual dental cleanings and exams.
- Report to your physician immediately if you think or know that you have had a seizure or seizure-like episode. Seek emergency care if a seizure involves lost consciousness or possible injury.
- Practice safe sex to avoid social diseases and unwanted pregnancy.
- If you use tobacco, talk to your physician about medications and programs to help you stop. Tobacco affects your brain as well as your lungs.
- Limit use of caffeine (coffee, tea, energy drinks, sodas, etc.).
- Develop a regular and sufficient pattern of sleep. Adults usually require seven to eight hours of sleep per night. Talk to your physician if you have trouble falling and/or staying asleep or if you continue to feel sleepy or tired during the day despite an adequate amount of nighttime sleep. Fatigue is a common effect of a TBI. It can be related to many factors including lack of activity, poor quality or quantity of sleep, medication side effects or over activity, to name a few. Fatigue limits a person's ability

or drive to accomplish tasks. You and your family are encouraged to speak with your physician if fatigue is a noted barrier to your plans.

- Talk to your physician about developing a suitable regular exercise program that fits your needs. Exercising 20 minutes, three times a week can have a positive effect on your physical and emotional health.



- Know your best target weight and develop a balanced and regular eating pattern to maintain your weight. Gradual weight gain can occur when you become less

“ Seek medical care for health concerns early to avoid protracted problems...”

physically active. However, obesity has many negative effects on health and self-esteem.

- Manage chronic health conditions in conjunction with your physicians’ help. Uncontrolled diabetes, hypertension, heart disease, sleep apnea and similar conditions can affect your long-term health and current ability to function at your highest level.
- Chronic pain is not common but can follow TBI. Post-concussive headaches rarely become chronic. Spasm and contractures, among other things, can cause pain. Untreated chronic pain is correlated with depression. You are strongly encouraged to work with your physician to identify an effective treatment approach to eliminate or significantly decrease the impact of pain. Treatment options may include medication, counseling, acupuncture, physical/occupational therapy and biofeedback, separately or in some combination.

- Seek medical care for health concerns early to avoid protracted problems, complications or more invasive care.

Substance abuse

Unfortunately, alcohol and substance abuse has played a major role in the incidence of TBI. Many individuals who abuse alcohol or illicit chemicals return to abuse after the TBI, to the greater detriment of their health and ability to reach their goals.

Alcohol and illicit chemicals affect the brain differently after TBI. Alcohol and illicit chemicals can increase seizure risk and the risk of additional brain injuries.

Long-term negative effects of alcohol use on the brain have been documented. The use of alcohol and illicit chemicals can magnify changes that may follow TBI, such as problems with initiation and drive; memory; attention; and emotion and behavior control.

Studies connect alcohol and substance abuse to poorer overall outcomes as related to success in returning to work, school, social and home life. Individuals who have had a pre-injury history of alcohol or substance abuse are strongly encouraged to seek consultation with a substance abuse counselor to develop a plan to avoid relapse into alcohol or substance abuse.

It is important to appreciate that you may need to make lifestyle changes to avoid relapse or abuse. Friends and families, work and recreation environments often

influence our decisions about alcohol and substance use. Speak with your physician, a rehabilitation psychologist or substance abuse counselor about strategies to maintain a healthy lifestyle.

Dating and intimate relationships

TBI can have an impact on intimate relationships including dating and marriage. Single adults with TBI report challenges to dating after their injury. Physical changes can influence one's self-image and confidence. However, cognitive changes can impact social skills as well. Brain injury is a unique experience and poses individual challenges.

As you move back into dating, do a self-assessment on your:

- Social skills
- Dating expectations
- Self-image
- Plans regarding sexual intimacy

Use your trusted friends and family to give you important feedback about your choices in dating.

A word about victimization: Unfortunately, individuals with disabilities are at increased risk of being taken advantage of in many areas including sexual exploitation. Never accept or allow physical, emotional or sexual abuse under any circumstances. Partners who do not accept your personal

choices or who demean or hurt you in any way do not have your best interests in mind.

Married individuals who have experienced a TBI sometimes experience role changes in the marital relationship. Spouses become caregivers, at least initially, and often take on many of the roles of the family.

As you return to family participation, you and your spouse may need to openly talk about your role as a spouse and parent and your contributions to home care and your sexual relationship. You are encouraged to understand that your spouse has acted in love by assuming additional roles and may be reluctant to relinquish or change roles, partly out of concern for your well-being.

Family members are encouraged to understand and appreciate that the individual with TBI may function in prior roles in a different way. While different, their new or amended approach is not necessarily wrong.

It is imperative that couples frankly discuss the changes in their relationship through the recovery process and beyond. This can be uncomfortable and cause those involved to feel threatened and defensive. Advocate for yourself and your marriage by seeking professional help from a counselor familiar with TBI.

"Make decisions based on your gut feelings. Don't let anyone push you into a decision you are uncomfortable with."

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor

Friendships

It may be difficult for your friends to understand TBI, as it has been for you and your family. They may not have received much information about TBI and its effects. In the absence of information, they may struggle to find a place in your life or a way to connect with you.

You and your family are encouraged to keep close friends educated and involved from the injury forward. Help them to understand your needs for friendship and how they can connect with you.

When initiating social contact, consider selecting specific and time limited tasks with one or two friends. An example would be going to a movie. It may be helpful for you to talk to your friends before going on outings as to your needs for accommodations.

As you feel comfortable, you can expand social outings. You are always encouraged to advocate for yourself by taking rest breaks, shortening activities, asking for accommodations (such as help getting out of the car) and putting limits on the types of social activities you prefer. Remember the things that make your friendships special and strive to be a good friend.

Some friends may not feel comfortable continuing the friendship, or you may find that some friendships were not as close as you may have thought. Look forward, and begin the process of reinforcing strong and positive friendships and making new friends.

Coping with change

Change is often a challenge for people regardless of the cause. There are three important things you can do to help yourself in navigating change.

- Be patient with yourself.
- Share your feelings and thoughts with your family and friends.
- Use your available resources of family, friends, agencies and professionals.

The injury event can create stress for you and your family. Remember that this is unfamiliar territory for all of you. Stress can cause problems in many areas of your life. It can create a sense of guilt, worthlessness, hopelessness, or feeling completely alone, among other feelings. Stress can also contribute to depression and anxiety.

The following recommendations may help your family cope during different phases of your experience. Family members should:

Take care of yourself

- Get plenty of rest, eat the right foods and get enough exercise.
- Take turns at the hospital with friends and family.
- Plan to resume some of your normal family activities.
- Ask friends to help with home tasks.

Try not to isolate yourself

- Try becoming acquainted with other patients and their families.
- Ask friends to visit you at the hospital or home.

- Ask the hospital volunteers to call on you.
- Visit with the hospital chaplain.
- Spend time with your other children (if it is one of your children who has the TBI).

Depression

Depression is defined as having significant feelings of sadness, helplessness, hopelessness and dissatisfaction to the extent that it interferes with one's ability to function well in life. There are many factors that contribute to depression, including a sense of loss, lack of help or resources to deal with life and financial strain.

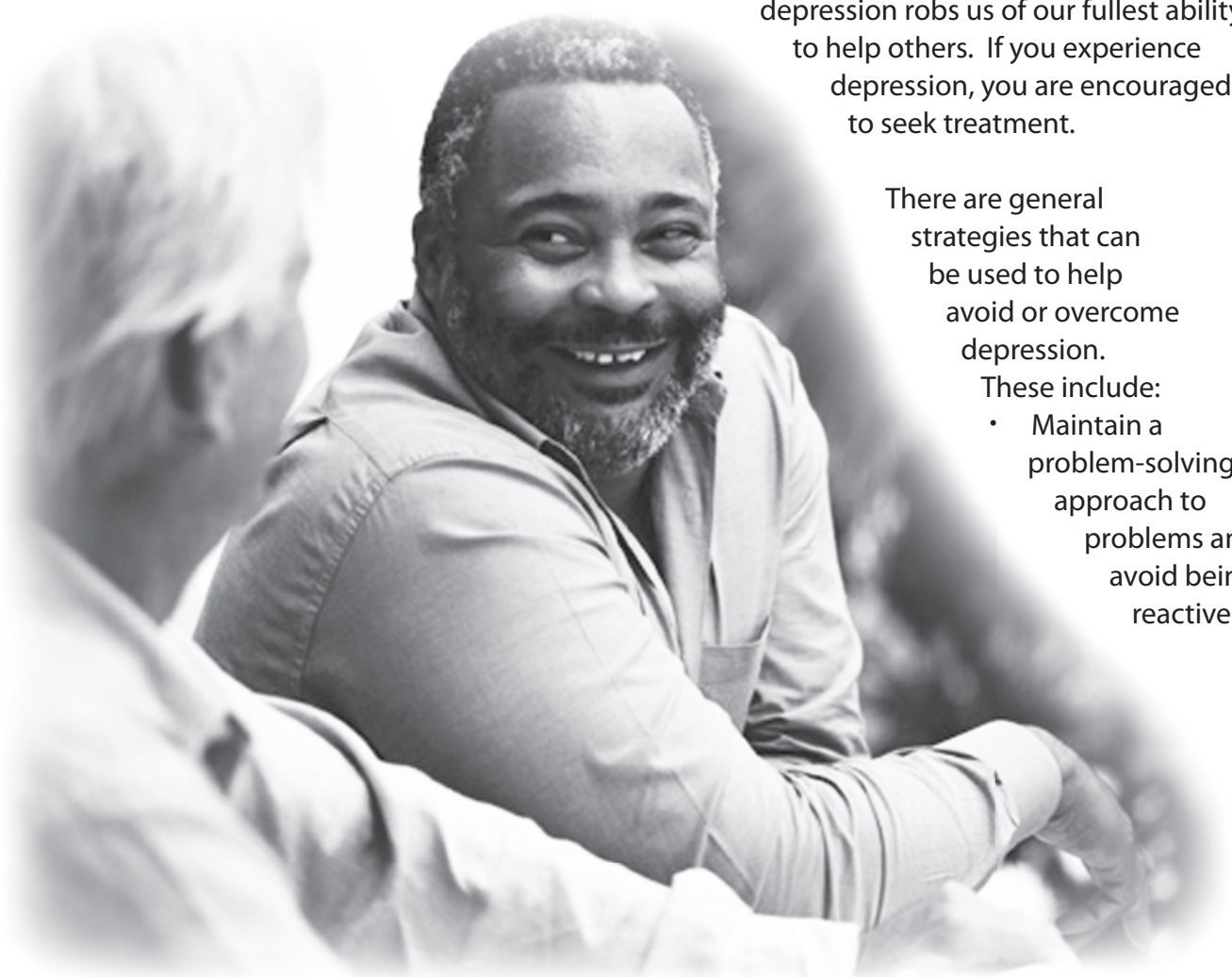
Individually, our own attitudes and approaches to problems play a major role as well. Depression is treatable. The best treatment for clinical depression includes a combination of medication and counseling. The goal of treatment is to help the individual learn new ways to handle problems, make life choice decisions to decrease problem areas and improve one's ability to face challenges.

Depression can affect the individual with TBI or family members, as all have experienced the injury event. Sometimes family members ignore their own needs for help due to a belief that they need to focus on their loved one with a TBI. In fact, depression robs us of our fullest ability to help others. If you experience depression, you are encouraged to seek treatment.

There are general strategies that can be used to help avoid or overcome depression.

These include:

- Maintain a problem-solving approach to problems and avoid being reactive.



Adopt a positive and hopeful outlook.

- Use your resources, friends, family, local agencies and professionals to help you manage challenges.
- Do not rehearse and replay negative thoughts or experiences.

" Use your resources, friends, family, local agencies and professionals to help you manage challenges. "

- Adopt a healthy lifestyle, including adequate sleep, a balanced diet and regular exercise.
- Avoid alcohol and illicit chemical use as this tends to exacerbate emotional problems.
- Participate in socialization opportunities on a regular basis.
- Be involved in meaningful life activities including volunteering, participating in faith-based activities and actively using your mind through reading and new learning.
- Establish short- and long-range goals to keep you directed and energized.
- Find something to look forward to daily.
- Be a thankful person.
- Establish mentors for all areas of your life and make it a point to learn from the good example and counsel of others.

Support groups

Dealing with the stresses of TBI can be difficult for families. The Brain Injury Association of Missouri (its local chapter and other various programs) can help through:

- Local support groups
- Information and referral
- Advocacy
- Social and recreation activities
- Educational programs and materials for people with TBI, families and caregivers

People who receive such services may:

- Collect useful information
- Gain support and understanding
- Learn problem-solving skills
- Enlarge their support system

Support groups are a place to share feelings and experiences with others who have walked in your shoes; a place to gain valuable information about TBI and resources; and even a place to have some fun. Support groups give families and people with TBI information regarding:

- Funding
- Legal protection
- Preparing a will
- Selecting a rehabilitation facility
- Planning for future rehabilitation, housing and employment
- Many other topics that are relevant issues to people with TBI

Keeping essential records

After initial hospitalization, many professionals will ask for detailed information about:

- Medical treatment and diagnosis
- School performance
- Insurance
- Rehabilitation
- Employment history
- Financial resources
- Community service involvement

Records of the information are very important. Begin keeping records at the time of hospitalization. Start with information including contact information for:

- Doctors
- Nurses
- Social workers
- Other therapists involved in your care

Ask for and keep copies of the discharge papers.

Save everything

Keep everything including:

- Insurance papers
- Benefits applications
- Responses and correspondence from important agencies, especially from your insurance company, Medicaid and Medicare
- Financial records (budgets, paycheck stubs, income tax records, bank statements, annual report on work history earnings)
- Educational records (assessment results and copies of individualized education plans - IEPs)
- Medical records

Build a file, making sure you note contact names on:

- Treatment programs and providers
- State and federal agencies
- Advocacy organizations

Organize information files. Suggested headings include:

- Medical history
- Insurance
- Financial resources
- Rehabilitation
- Education/work
- State and federal agencies
- Resources

Be sure to include information related to benefits:

- Eligibility for services
- Correspondence
- Services offered
- Log of interactions
 - Date(s)
 - Contact person
 - Address and phone number
 - Notes from conversations

Ask for help

If you need assistance or have trouble, ask for help. Refer to the Resources section in this book for information about various supports and services.

“Keep a journal from day one. You will never know how important a name, hospital stay or medicine will be. Sometimes these facts are needed years later. A journal is also a way to record emotions and stages of recovery.”

- Sue Orton, St. Louis, Mo.
Mother of a TBI survivor



Child and adolescent brain injury

When discussing brain injury, especially in children and adolescents, it is useful to first understand brain development. Aleksandr R. Luria, considered by many to be the father of modern neuropsychology, proposed that brain function develops in a sequence:

- *Stage 1:* This stage begins before birth and continues shortly thereafter. The areas of the brain responsible for basic arousal and attention mature.
- *Stage 2:* This stage overlaps the first one. During this time, functions essential to the survival of the newborn infant mature. These areas include basic sensory and motor functioning.
- *Stage 3:* This stage continues through the preschool years. The areas of the brain continue to be responsible for refining the basic functions developed

during the first and second stages. During this stage, motor movements are refined and secondary auditory and visual skills develop.

- *Stage 4:* This stage occurs between the ages of 5 to 8. This stage sees the development of the posterior areas of the brain. This development links perception with those areas responsible for basic academic skills, such as reading, math and reasoning.
- *Stage 5:* This stage takes place during early adolescence. The frontal lobes mature. This is the area of the brain responsible for organizing input from the senses and planning a response to that input.

Brain injury for a child or adolescent poses different challenges and an appreciation for child development. A child's brain

"Always remember the child you love is still deep inside the TBI survivor. You are their voice when they are recovering."

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor

continues to grow and develop in a process wired from conception through late adolescence. The adult brain is fully developed with critical cortical pathways already established and interconnected. An injury to a young brain affects recovery and ongoing development.

This chapter summarizes critical information pertaining to injury and recovery. More detailed information should be obtained from pediatric treatment providers and brain injury resources.

Like adults with brain injury, children can experience a myriad of effects from the initial trauma that can include swelling, contusions, lacerations, skull fracture and chemical cascading as the brain reacts to the trauma.

A primary goal in emergency care is evaluation for bleeding, swelling, skull fracture and other injuries that the child may have experienced. Initial care focuses on reducing swelling, stabilizing neurochemical activity, and preventing secondary complications including infection, pneumonia, blood clots and seizures.

Medications and surgery may be necessary during this phase in particular. While the child is often confused, agitated or possibly unconscious, parents are frequently very anxious and fearful as they try to understand their child's condition and make necessary decisions about the child's care.

The child may need care in a PICU (pediatric ICU) or neuro-ICU. Parents often report a sense of shock in seeing their injured child with tubes and other medical equipment attached. There is a critical need for information, but the parents may be emotionally challenged to manage the flow or lack of information at times.

Parents may encounter many specialists working on their child's case to manage the trauma and prevent or treat secondary conditions. One specialist, a physical medicine and rehabilitation physician (PM&R), is also referred to as a physiatrist. The treating physician may initiate rehabilitation wherein a physical, occupational and/or speech pathologist may begin a process of assessing the child's immediate rehabilitation needs and begin establishing a treatment plan.

Other specialists may become involved in the child's overall care and well-being, including a nutritional specialist, child life specialist, orthopedic specialist and recreation therapist. A physician also may request that a neuropsychologist or rehabilitation psychologist become involved to provide education about the injury and its effects as well as support and guidance.

As the child's condition stabilizes, he or she is likely to be moved to a regular medical unit of the hospital or possibly to a rehabilitation unit. It is at this time that rehabilitation efforts are likely to be fully initiated. The child is likely to receive daily physical, occupational and speech therapy.

Rehabilitation is directed toward continuing the healing process and providing stimulation and activities to restore injured skill areas. If the injury is such that areas of the brain cannot perform their typical function, surrounding areas may be recruited, through stimulation and practice, to assume some of the roles of the injured area.

As the child recovers, weaker skill areas will show improvement. The team will work with the child and parents to problem solve and develop strategies that facilitate and enhance functioning.

A social worker will likely provide the family with education, support and useful resources. A social worker may also serve

as a bridge of communication between the treatment team and the family. The neuropsychologist or rehabilitation psychologist will likely participate in assessing the child's level of recovery as it relates to focus of treatment, providing ongoing education and support to the child and family, and working with the team in planning for the next steps in care beyond inpatient treatment. The treatment team will meet at least weekly to discuss the child's progress.

The family should expect to be involved in periodic family conferences where team members will discuss a proposed treatment plan and the child's progress with the parents. This is a critical time when the family begins to be actively



involved in setting treatment goals and plans.

When the primary treating physician believes that the child is stable and not

“ Recovery for children occurs over three to five years. ”

in need of extensive nursing and medical care, the child will likely be discharged to outpatient medical rehabilitation services. These services may be provided through the outpatient services of the hospital or a community-based treatment program. Parents are generally advised of the discharge plan in a timely manner to allow appropriate transition tasks for bringing the child home and making necessary arrangements to transport the child to therapy.

An outpatient program may be five days a week or less depending on the child's needs and family situation. Often, this is the stage when the team begins planning for eventual return to school. Many specialty pediatric outpatient programs include special education teachers. The teacher or social worker will likely obtain consent and contact the school to obtain previous school records and begin identifying special education resources available in the school.

The school may begin homebound

instruction or provide education materials to be completed by the child in the rehabilitation program. This is a graduated process entirely determined by the child's ability to meet academic demands.

Parents often note that their child has made strong progress in recovery from the early days of brain trauma. The child is likely engaged in active therapies and not receiving or in need of as much of the parent's attention during treatment. This is often a time when parents include siblings to address their needs for information about their injured brother or sister and assist the sibling to understand their role during the recovery process.

Typically, therapy intensity declines over time, and therapies are phased out as goals are met. The team will begin the process of developing appropriate education-specific recommendations for physical, occupational and speech therapy in the school, if indicated.

The treatment team may recommend a school conference wherein school personnel visit the treatment facility and meet with the team and parents to discuss the education and therapy needs of the child. This may include nursing, paraprofessional support, school counselor or social work support, and special education services including physical, occupational, speech therapy, and special education instruction and modifications.

Before the child returns to school, it is useful to determine whether the child's needs require an IEP (individual education

plan) or 504 plan, as required by the IDEA (Individuals with Disabilities Education Act). An IEP is often initiated if the child has a disability, noted to interfere with educational progress, that requires special education services (physical, occupational, speech therapy, special education/classroom, nursing). An IEP identifies the nature of the disability, the effect on academic progress, special education services, goals of the services, and structure of how the services are to be delivered and measured.

The process of developing the IEP must include the parents as well as special services team members. The IEP must be reviewed annually to monitor progress, establish or modify goals, or terminate the services. The special education coordinator for the school supervises an IEP. An IEP may be reviewed earlier if a need is identified.

A 504 accommodation plan involves identifying beneficial accommodations for a child with disabilities who does not meet the criteria for an IEP but who would profit from services not provided by special education. This plan is also developed in tandem with the parents, teachers and administrators involved in providing the accommodations. Examples of accommodations include allowing extra time for the child to pass between classes,

providing a set of text books to be kept at home and decreasing the number of test items on an in-class test.

Whereas recovery from a traumatic brain injury for an adult may occur over one to three years, the length of recovery is extended for a child because of the concurrent ongoing physiological growth and development of the body and brain. Research suggests that the developing brain may be affected more adversely by the neurochemical changes that follow brain injury.

TBI recovery for children occurs over three to five years. As with adults, much of the recovery occurs in the first year. Given the ongoing natural maturation of the brain, certain changes may not be noted until later in the child's life. Specifically, the more complex cognitive abilities of reasoning and abstract thinking that naturally develop through the teen years. Subsequently, difficulty with reasoning in a younger child may not be atypical for the child's age or as apparent relative to children without a history of brain injury.

The effect of childhood brain injury

The effect of brain injury varies from child to child. This is partly because every brain injury differs in type and severity. In addition, recovery from brain injury is complex and is affected by many non-

"Find a moment for yourself - even if it is just to read a good book or take a short walk around the plaza of the hospital or a bubble bath. It will refresh you."

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor

injury factors, such as the child's age at the time of the injury, pre-injury functioning and family supports.

The recovery process is complex, and health care providers cannot predict the precise outcome for a specific child. Some risk factors are known to increase the likelihood of certain types of outcomes. More severe brain injury is associated with a greater likelihood of impairment.

Children who are injured at a younger age (less than 7 years old) are at greater risk for long-term deficits in functioning. Prior learning tends to be retained following injury, so children 6 years and older benefit from having gained previous knowledge. New learning skills are often impaired after injury.

There are no common patterns of recovery from brain injury. The effects of injury may be apparent immediately after the injury and then improve. Some problems may resolve completely, and some effects may be permanent.

Injury to the developing brain may have an immediate permanent effect that in the future alters subsequent developmental patterns. For example, if the injury is severe enough to alter basic language skills, then the development of higher order language skills at older ages also will be affected. If there are deficits in such foundation skills, later emerging skills are also impaired.

Some effects may not be apparent at the time of injury but may become apparent

over time. These effects surface for various reasons. This may be because the brain structures damaged by the injury may not have been fully mature at the time of injury.

While the brain continues to develop, skills associated with injured structures may not develop to the same degree. For example, if a child's injury at age 4 affects areas of the brain related to decoding written text (such as visual perception and phonological processing), reading problems may not be apparent until the first grade when such skills are expected to emerge.

A child with organizational problems after an injury at age 10 might perform adequately in elementary school but have significant academic difficulties in junior high when demands on organization and self-monitoring increase. The child may be initially well-adjusted but develop emotional or behavioral problems later due to academic failure or the loss of friends.

Given that the child's brain is developing over a number of years, it is important to appreciate that needs and challenges may change over time. This calls for a higher degree of diligence in monitoring the effects and readiness in order to adapt the environment to meet a change in needs that may emerge.

While long-term medical problems are not common following TBI, the following conditions may occur:

- Fatigue is the most common

complaint, often resulting in diminished endurance.

- Headaches may be a complication after a TBI, especially immediately following the injury.
- Seizures may occur due to scarring or the brain injury, but they are not a frequent consequence of injury. Seizures are intense disturbances in the activity of the central nervous system caused by abnormal electrical discharge in the brain.
- Bladder and bowel control may be compromised depending on the severity of the brain injury.
- Orthopedic impairments may cause motor dysfunction.

As with adults, areas of potential change in children who have had a traumatic brain injury include changes in:

- Vision, hearing, smell/taste
- Motor skills: coordination, ambulation, balance
- Attention and concentration
- Auditory, visual and divided attention
- Auditory and visual processing speed
- Response time
- Learning curve
- Long-term recall
- Visual vs. auditory memory skills
- Memory as task complexity increases



- Prioritizing information
- Simultaneous processing ability
- Abstract thinking skills and problem solving

“ Depression is the most common emotional reaction following brain injury in older children...”

- Planning and organizational skills
- Flexibility in thinking styles
- Organizing verbal responses for open-ended questions
- Organizing written responses
- Maintaining a topic
- Understanding idiomatic/figurative language
- Comprehension in general discussion
- Word finding
- Initiation of speech
- Turn-taking skills/behavior
- Eye contact
- Nonverbal communication
- Use of interpersonal space
- Use of gestures

Families report that emotional and behavior changes place the greatest strain on the family members. Families often feel there are significant changes in the child's personality.

Specific changes observed in children following brain injury can be affected by the age of the child at the time of the TBI and the circumstances surrounding the injury itself.

Some of the emotional and behavioral issues affecting children with a traumatic brain injury include:

- Depression - Depression is the most common emotional reaction following brain injury in older children and adolescents. There is a marked and sustained lowering of emotions and a lack of ability to respond to stimuli. Children might exhibit symptoms of sadness, loss of interest in social and physical activities, feelings of worthlessness and hopelessness, or a sullen or despondent attitude.

In extreme cases, children may present with suicidal ideations. Physical symptoms of depression also may be present and include changes in appetite and weight, loss of energy, and sleep disturbances.

- Anxiety - Children with brain injury may present with signs of generalized anxiety. Symptoms can include nervousness and restlessness. It is not uncommon for children who have experienced a life-threatening event as the precipitator of their brain injury (such as being in a motor vehicle accident or being hit by a car) to avoid specific places and activities related to the precipitating event. These children may also have recurrent nightmares about the event, though this is uncommon.
- Difficulty accepting changes in self relative to pre-injury functioning -

One of the biggest challenges facing an individual following a brain injury is learning to accept new, albeit altered, abilities and realities.

This conflict between the “old vs. new” self is especially problematic for older children and adolescents who may have had a clear image of who they were before the brain injury. This issue is less salient for children who experience their injuries at an early age, since they have less awareness of themselves prior to the brain injury.

- Difficulty accepting changes in self relative to peers - A related challenge for a child is accepting changes that the child or adolescent feels makes them different from their peers. An example might be physical challenges that affect walking (unsteadiness or limping), speech (slurring) and hand use (tremor or weakness).
- Cognitive changes viewed as differentiating the child from peers include memory problems (forgetting conversation topics or names), learning difficulties (having special education services or being slower in learning) and processing speed (trouble keeping up with

conversations, difficulty responding to questions and comments, or being slower in finishing work).

- Anger control and emotional lability - Emotional lability refers to rapid, volatile shifts in mood with more intense reactions than expected. Anger control issues often occur when a child is less able to tolerate frustration, reason about situations, and moderate their emotional and behavioral reaction.

Poor anger control and emotional lability can result in a sudden, violent verbal and/or physical display of anger, which may be related to a precipitating situation, or may appear to serve no obvious purpose. Characterized by both a sudden onset and abrupt end, these outbursts, however, are typically excessive or exaggerated relative to the precipitating events.

For example, a child with a brain injury may become extremely agitated and throw things upon hearing the news of a minimal change in scheduled activities. Children who exhibit behavioral outbursts may be remorseful and apologetic after the event.

“Look for humor in everyday situations. It will keep you healthy during this stressful time.”

- Debby Beffa, Chesterfield, Mo.
Mother of a TBI survivor

- Impulsivity - A child with a brain injury may act or speak without thinking how his or her actions or words will be viewed as harmful or inappropriate by others.
- Poor judgment - The inability to list the contributing factors, alternative choices and realistic outcomes of decisions makes it difficult for children with brain injury to work through a sound, productive decision-making process.
- Disinhibition - This term reflects the lack of restraint in children with brain injury regarding socially unacceptable behaviors such as yawning or burping loudly.
- Dependency - Teachers and peers may notice that, upon returning to school, the child may develop a complete or disproportional reliance on particular individuals, schedules or rituals.
- Poor motivation - Regardless of pre-injury performance, the child may now attach little or no significance to achievement or participation in activities and events valued by others.
- Apathy - Children with brain injury may appear indifferent to events and their surroundings.
- Lethargy - The child may often seem sluggish, or even appear to have fallen asleep. It may be extremely

difficult to arouse the student from this cessation of physical and mental activity.

- Teen dating and sexuality - Teens naturally begin exploring intimate relationships and express an interest in dating. It is important for parents to talk to their teens about their expectations of the teen regarding dating and sexual activity. It is important to ensure that teens understand the emotional demands of sexuality and intimate relationships.

Parents need to ensure that teens are knowledgeable about pregnancy and social disease risks. After a brain injury, teens may feel more self-conscious and vulnerable to the influence of others. Their ability to read social cues and make important social judgments may be affected by the brain injury. Parents need to develop effective communication with their teens to foster discussion about good decisions.

Given the changes in cognitive functioning, precipitants of inappropriate behavior typically relate to:

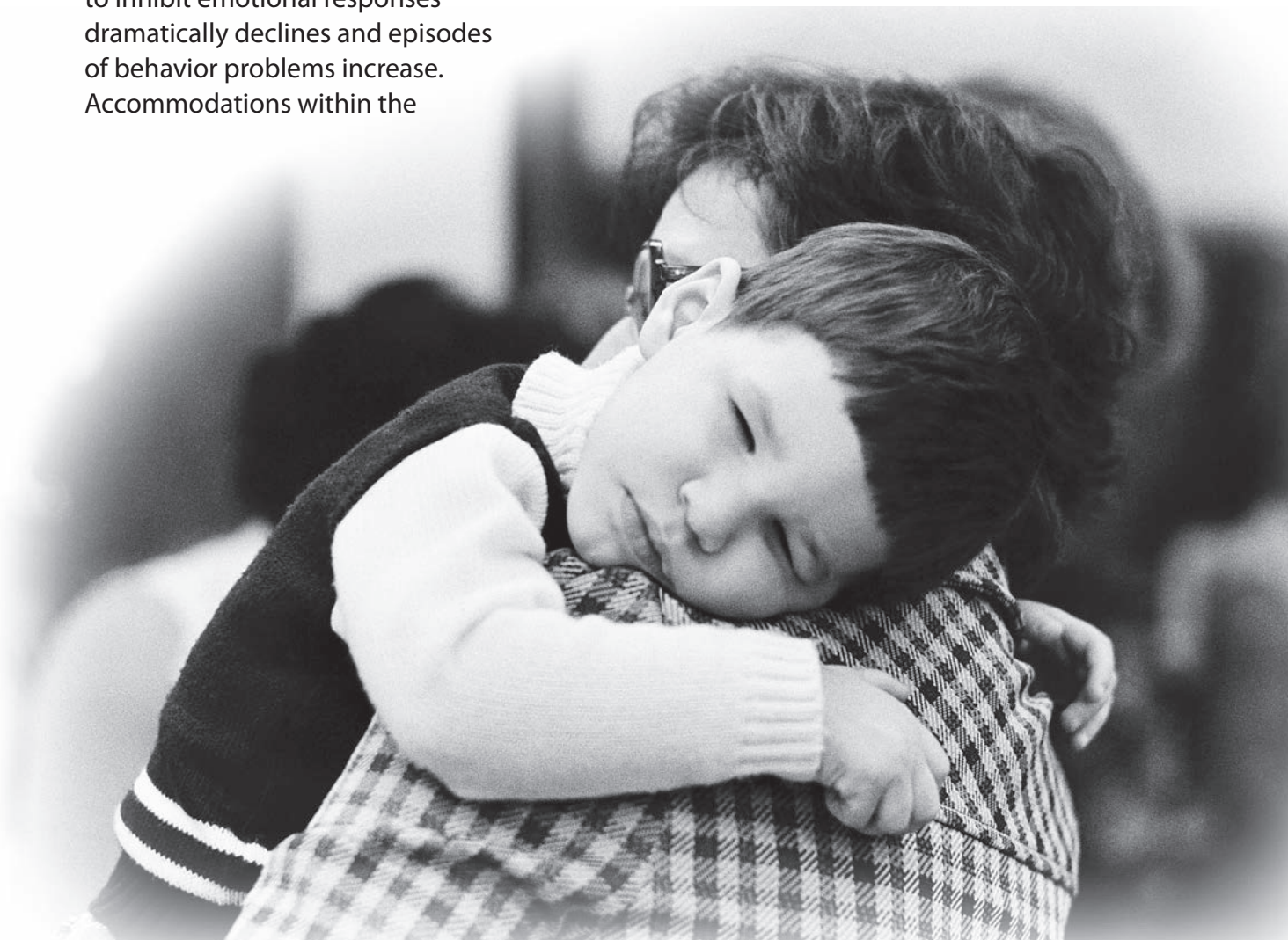
- Overstimulation - This occurs when a child feels overwhelmed with their situation and surroundings. Noise, visual stimulation, the activity of people around the child and demands on the child can lead to overstimulation. It is important to be

proactive by understanding what leads to overstimulation and helping to modify the child's surroundings to decrease the likelihood of this happening. Behaviors such as acting out and poorly-controlled emotion can occur as a result of feeling overstimulated.

- **Fatigue** - Children with brain injury often complain of chronic fatigue. Children's ability to attend to classroom content and social events is directly dependent on their level of fatigue. When children become excessively fatigued, their ability to inhibit emotional responses dramatically declines and episodes of behavior problems increase. Accommodations within the

school day to minimize fatigue (such as allowing for frequent rest periods during a day) are necessary to enhance a child's functioning.

- **Unexpected changes** - Children with brain injury are poor responders to unexpected change in routine. Their ability to understand change and be flexible may be compromised. The demands of change can cause overstimulation, and the child may react with frustration, anger or tearfulness. Accommodations within the school environment, such as an emphasis on a highly structured day



and adequate forewarning of transitions, are necessary to minimize episodes of behavior problems for children with brain injury.

"Children with brain injury often complain of chronic fatigue."

Interactions with peers, family members, and others are often affected by a brain injury. Children with brain injury might display the following behaviors:

- Decreased social skills, such as turn-taking and topic maintenance, that influence the ability to make friends.
- Decreased awareness of social cues.
- Decreased awareness of self and decreased insight that affects the ability to relate to others. For example, the child might be reluctant to seek assistance when needed.
- Being distracted in noisy surroundings - This may cause an inability to keep up with social conversation and a sense of feeling lost in social situations.
- Bossy and argumentative - A person who is demanding and seems to pick fights can negatively impact social relationships with others.

- Poor responsibility and dependency - A lack of good judgment or being willing to account for their actions may cause strains in social relationships.
- Inappropriate sexual behavior and/or language.
- Suggestibility - A child with a brain injury might be more easily led or influenced by peers.

Shaken Baby Syndrome

Shaken Baby Syndrome is a violent criminal act that causes traumatic brain injury. Shaken Baby Syndrome occurs when the perpetrator aggressively shakes a baby or young child. The forceful whiplash-like motion causes the brain to be injured.

Blood vessels between the brain and skull rupture and bleed. The accumulation of blood causes the brain tissue to compress while the injury causes the brain to swell. This damages the brain cells.

Shaken Baby Syndrome can cause seizures, lifelong disability, coma, and death.

Irritability, changes in eating patterns, tiredness, difficulty breathing, dilated pupils, seizures and vomiting are signs of Shaken Baby Syndrome.

A baby experiencing such symptoms needs immediate emergency medical attention.

Self-advocacy: parent to child

In *What Psychotherapists Should Know About Disability*, Rhoda Olkin writes, "With the predominant focus on negative attitudes toward disability there is less understanding of positive, caring, loving, intimate relationships between an able-bodied person and a person with a disability."

Parents need to be advocates for their child who has experienced a traumatic brain injury and provide watchful attention and intervention. From recovery and beyond, parents will need to monitor their child's needs in all areas of life and well-being: academically, physically, socially and emotionally.

However, it is vital that parents also work with their child to help them learn to speak out regarding their own needs. Parents are vital in helping their child interpret the injury event and its impact and helping their child integrate the experience into his or her life in a way that fosters self-worth and growth. As the child moves through adolescence into adulthood, parents are encouraged to teach their child to become independent as a self-advocate.

The young person, with the help of family and the larger rehabilitation community, will become adept at identifying and using accommodations and resources to work toward reaching short- and long-term goals.

"I had the best medical care in the world, but honestly, the positive influence of my mother after my injury was the best therapy I could have ever received."

- Andrea Buening, Seneca, Mo.
TBI survivor



Brain injury and the aging brain

The transition into late adulthood is accompanied by a number of physical, psychological and social changes. In addition to offering opportunities for personal growth and life enrichment, advancing age is also associated with diminished sensory functioning including problems with hearing and vision and the onset of chronic medical conditions like diabetes and heart disease and orthopedic conditions such as arthritis.

Adults age 65 and older are also at increased risk for experiencing a traumatic brain injury. Older adults striking their head on the ground or some other hard object following a fall is the leading cause for these injuries. In addition to the sensory deficits and chronic medical conditions that are common with age, medication side effects may also compromise the physical functioning

of older adults and contribute to their increased risk for falls and TBI.

While a TBI can happen at any age and in a number of ways, it is known that older adults are confronted with unique challenges following a TBI. For example, older adults have been found to experience an increased incidence of posttraumatic infection and seizures, subdural hematomas (bleeding in the subdural space), and delayed neurosurgical complications following moderate to severe TBI.

Of particular note, chronic subdural hematomas have a peak occurrence in the sixth and seventh decades of life and may develop after a very mild event such as a bump to the head. Typically the result of a slow leak from an injured blood vessel, a chronic subdural

“Be realistic. Your recovered family member will be forever changed. Love him as he is, and be thankful that you still have him in your life.”

- Arpie Vermillion, Seneca, Mo.
Mother of a TBI survivor

hematoma may develop over days or weeks before the accumulating blood exerts sufficient pressure on the brain to cause symptoms, including confusion or loss of consciousness. Older adults who experience a significant change in their mental status during their recovery from a TBI need to be evaluated by their physician to rule out the presence of a subdural hematoma. Older adults may also require longer hospitalizations and rehabilitation stays to achieve their optimal level of functioning.

Many factors contribute to the unique challenges and increased complications that older adults may experience following a moderate to severe TBI. For example, throughout one's lifetime the brain is exposed to a number of minor insults with each of these events leaving the brain that much more vulnerable to future injury. Additionally, the loss of brain cells and diminished blood flow to the brain that accompanies normal aging may compromise the brain's ability to repair itself and recover from injury.

In addition, the preexisting medical conditions that many older adults have may also complicate their recovery from a TBI. Similarly, individuals with a TBI may require surgical intervention (on their brain or another part of their body), and it is known that older adults may take longer to fully recover following surgery.

While older adults may require longer hospitalizations following a significant TBI, research shows that they benefit from rehabilitation services and often

experience improved function and quality of life following treatment.

Common consequences of TBI

TBI can impact any aspect of a person's being, including their cognitive and emotional functioning, personality and behavior. The vulnerability of certain areas of the brain following a TBI often contributes to a constellation of symptoms that includes deficits in attention, speed of processing and behavioral responding, learning, expressive and receptive language functioning, memory, and problem-solving abilities.

Depression, anxiety, irritability, impulsivity and emotional lability are also relatively common among older adults with a history of TBI. It is noteworthy that when compared to younger survivors of TBI, older adults with a history of TBI may be at an increased risk for the delayed onset of depression and anxiety.

Distinguishing TBI-related cognitive impairments from the effects of other medical conditions common in older adults may be difficult. For example, hypertension has been associated with general cognitive dysfunction, including memory impairment.

Cardiovascular disease can compromise speed of processing, attention, expressive language and memory. Congestive heart failure can contribute to a significant decline in cognitive functioning, including impaired attention.

Deficits in cognitive processing speed and memory are common in elderly survivors of stroke. While TBI-related cognitive deficits would be expected to improve as recovery progresses, impairments related to other medical conditions may not respond to rehabilitation interventions.

Also, some adults who incur a TBI have a history of cognitive difficulties that was not recognized prior to their TBI. However, following their brain injury, these preexisting cognitive deficits may be exacerbated.

For example, an older adult who has a history of hypertension and cardiovascular disease may have experienced mild attention or memory problems prior to their TBI. The cognitive dysfunction was not recognized until after the injury.

Treatment following TBI

Treatment following a significant TBI often includes cognitive and physical rehabilitation, psychological and social support, and medications to treat emotional and behavioral symptoms. Immediate treatment typically includes acute trauma and neurosurgical care and acute inpatient hospitalization and rehabilitation.



Post-acute rehabilitation services may include comprehensive day treatment programs, transitional living programs, home-based rehabilitation, adult day care centers and residential treatment programs. Rehabilitation programs should involve a number of different treatment

of cognitive processing and behavioral responding is common after a TBI.

Allowing a TBI survivor appropriate time to process information and express thoughts may alleviate frustration and ensure that their needs are identified. Encouraging the use of memory strategies and cognitive aids such as a daily organizer and prioritized checklists may promote their level of independence.

Deficits in social skills and decreased social activity are also common following TBI. Interventions designed to enhance social functioning and promote social activity may be beneficial.

Assessment and treatment of psychiatric conditions (such as depression and anxiety) are a primary concern following TBI. However, distinguishing symptoms of depression from symptoms related to TBI can be difficult. For instance, sleep disturbance, irritability, and difficulties with concentration and memory are common to both depression and TBI.

Additionally, damage to the frontal lobes of the brain can result in a loss of interest and diminished initiation, which may be mistaken for symptoms of depression. A psychological evaluation by a qualified mental health provider who is familiar with TBI is important to clarify the emotional well-being of a person who has sustained a TBI. Helping a TBI survivor initiate activities that are consistent with their current level of functioning and asking them about their outlook on the future may help identify

“...older adults are confronted with unique challenges following a TBI.”

providers (such as speech and physical therapists) who offer services that are tailored to the needs of the individual. Moreover, patients and their families should play an integral role in the planning and design of the program.

While treatment recommendations should be tailored to the unique strengths and needs of the older adult, many TBI survivors benefit from some general suggestions to promote their functioning. For instance, reduced frustration tolerance and difficulty dealing with ambiguity or excessive stimulation are common following TBI. Accordingly, maintaining a structured, predictable, and low stress environment may be beneficial.

Encouraging and assisting a person who has had a TBI to focus on a single task at a time and avoid “multi-tasking” when possible may promote cognitive efficiency by minimizing demands on divided attention. Also, diminished speed

the presence of depression. Expressing hopelessness is a sign of depression.

Psychotherapy and counseling services may be beneficial for many older adults who have experienced a TBI. In addition to addressing psychiatric disorders and behavioral disturbance, counseling can be utilized to provide education about TBI and recovery and to promote coping and problem-solving skills, self-awareness, the reestablishment of intimate and social relationships, and positive lifestyle change. Because TBI impacts the entire family system, psychotherapy services should be

extended to family members and significant others as needed.

Having a TBI increases one's risk of a future TBI. Proactive interventions, including addressing sensory deficits (through hearing aids and glasses) and treatable health conditions (such as hypotension), evaluating the necessity and side effects of medications, and promoting improved physical and emotional well-being, should be initiated to minimize the risk of a future TBI.

"Be proactive about your role in recovery. Practice tough love. Be aware that TBI patients are often childlike and will certainly beg to come home. Don't permit him or her to leave a facility until all treatment options have been completed."

- Arpie Vermillion, Seneca, Mo.
Mother of a TBI survivor



Resources

There are many resources that may be helpful for brain injury survivors, their family members and friends. The following pages list a variety of resources for information, support and services. This list is not meant to be comprehensive, but to serve as an introductory guide. Resource information may change over time. To obtain current resource information, access the Missouri Greenbook online at: **<http://health.mo.gov/living/families/shcn/publications.php>**

You can also contact the Missouri Department of Health and Senior Services at 800-451-0669 to be connected to a service coordinator in your county who can assist you with navigating available resources.

The Brain Injury Association of America (BIAA)

Founded in 1980, the Brain Injury Association of America is a national organization serving and representing individuals, families and professionals who are touched by a life-altering, often devastating, traumatic brain injury. The BIAA has a network of more than 40 chartered state affiliates to provide information, education and support to assist the 5.3 million Americans currently living with traumatic brain injury and their families. Information about the BIAA affiliate in each state can be found on the BIAA website or by calling the association's toll-free number listed below.

Toll-free phone: 800-444-6443

Website: www.biausa.org

"Survivors are valuable mentors to other survivors. It is a pleasure to be a role model to others. Get involved with a support group. It will lead you to a world of resources."

**- Andrea Buening, Seneca, Mo.
TBI survivor**

The Brain Injury Association of Missouri (BIA-MO)

The Brain Injury Association of Missouri is a community-based, 501(c)3 nonprofit organization serving people with brain injury, their families, caregivers, physicians, therapists, case managers and others throughout the state. Founded in 1982 by a group of parents, BIA-MO works through regional chapters and support groups across Missouri. The BIA-MO is a chartered state affiliate of the Brain Injury Association of America. Contact the BIA-MO for brain injury information, resources and a schedule of times and locations of support groups in your area.

Toll-free phone: 800-444-6443

Website: www.biamo.org

State and Federal Agencies

Missouri Department of Health and Senior Services (DHSS)

Adult Brain Injury Program (ABI)

The ABI Program assists Missouri residents, ages 21 to 65, who are living with a traumatic brain injury (TBI). Through service coordination, the program links individuals to resources to enable each person to obtain goals of independent living, community participation and employment. Individuals who meet financial eligibility requirements may also receive community-based rehabilitation services to help achieve identified goals. Rehabilitation services include counseling, vocational training, employment supports and home- and community-based support training.

Toll-free phone: 800-451-0669

Website: <http://health.mo.gov/living/families/shcn/ahi.php>

Traumatic Brain Injury

DHSS provides general information and helpful resources on the topic of Traumatic Brain Injury.

Toll-free phone: 800-451-0669

Website: <http://health.mo.gov/living/healthcondiseases/tbi/index.php>

Brain Injury Guide and Resources

The Brain Injury Guide and Resources web site is a web based training on traumatic brain injury (TBI) and is a tool for those seeking to cope with and understand TBI. Developed through a collaboration with DHSS and the MU Department of Health Psychology, the website is designed specifically for people who, in their professional lives, may come in contact with people who have suffered brain trauma (e.g. police officers, social workers, military professionals). These professionals may not have expertise handling situations that may occur when they encounter someone who has experienced a brain injury. Ultimately, family members of people with brain injuries may be the biggest users of the site.

Website: <http://braininjuryeducation.org/>

Special Health Care Needs (SHCN)

DHSS Special Health Care Needs provides service coordination and services for children, youth and adults with disabilities. Programs available through SHCN include:

- Children and Youth with Special Health Care Needs Program – ages birth to 21

- Healthy Children and Youth Program – ages birth to 21
- Medically Fragile Adult Waiver Program – ages 21 and over

Service coordination is available free of charge to all individuals who are eligible for SHCN programs regardless of income.

Service coordination includes:

- Evaluation and assessment of needs
- Information and education
- Assistance in locating and accessing medical care, housing, counseling, transportation and rehabilitation services

Individuals may contact a service coordinator or may be referred, with permission, by physicians, family, friends, hospitals or rehabilitation centers, service agencies, and support organizations. Contact SHCN for service coordination services and other services available through the SHCN program.

Toll-free phone: 800-451-0669

Website: www.health.mo.gov/living/families/shcn/

Division of Senior and Disability Services

The DHSS Division of Senior and Disability Services provides a variety of services to eligible disabled adults between the ages of 18 and 59, as well as seniors over the age of 60 who are recipients of MO HealthNet. Contact the division to request an assessment for home and community-based services.

Toll-free phone: 866-835-3505

Website: www.health.mo.gov/seniors

Missouri Department of Social Services (DSS)

The Missouri Department of Social Services is the agency that administers MO HealthNet (formerly known as Medicaid), income maintenance/assistance and food stamps. Some individuals who are injured will need rehabilitation and long-term care or supports for a period of time after hospital discharge while others may need them for a lifetime. Insurance may not cover all of these services. In addition, some state agencies may require MO HealthNet eligibility or proof of ineligibility in order to receive their services. Visit the DSS website for more information on the programs you are interested in. Contact your local DSS office for assistance.

Phone: 573-751-4815

Website: www.dss.mo.gov

MO HealthNet

MO HealthNet is a division of DSS that purchases and monitors health care services for low income and vulnerable citizens. The agency assures quality health care through the development of service delivery systems, standards setting and enforcement, and education of providers and participants. The agency is fiscally accountable for maximum and appropriate utilization of resources. The MO HealthNet Division is responsible for the administration of services provided in accordance with Title XIX, Public Law 89-97, 1965 amendments to the federal Social Security Act, 42 U.S.C. Section 301.

Phone: 573-751-3425

Website: www.dss.mo.gov/mhd/

Missouri Department of Elementary and Secondary Education (DESE)

Division of Vocation Rehabilitation (MDVR)

DESE's Division of Vocation Rehabilitation (MDVR) can assist individuals who want to work but who have disabilities that keep them from finding or keeping a job. The Vocation Rehabilitation (VR) program specializes in employment and training services. A VR counselor will determine your eligibility for services. To be eligible, you need to have a physical or mental impairment that causes problems with working and need VR services to be successfully employed. Once eligible, you will work with a counselor to develop a plan for your rehabilitation. VR will provide vocational information and guidance, allowing you to make informed choices about your vocational plan.

The MDVR Independent Living (IL) program provides services to people with disabilities to increase their independence and their opportunity to participate in day-to-day life within their communities. There are 22 Centers for Independent Living (CILs) statewide that offer independent living services. The CILs are funded through Vocational Rehabilitation grants and are managed by people with disabilities who have been successful in establishing their own independent lifestyles. Call or visit their website to see if you are eligible for their services.

Phone: 573-751-3251

Toll-free phone: 877-222-8963

Website: www.dese.mo.gov/vr/vocrehab.htm

Missouri Department of Mental Health (DMS)

Division of Developmental Disabilities (DD)

The DMH Division of Developmental Disabilities provides support services to eligible persons who have developmental disabilities and their families. DD provides a wide array of services that can be obtained through agencies, known as regional offices, located throughout the state. The primary responsibility of regional offices is to provide funding for services and assistance to families who have young children with developmental disabilities, as well as adult persons with developmental disabilities. Call or visit their website to locate a regional office in your area of the state.

Phone: 573-751-4054

Website: www.dmh.mo.gov

Missouri Veterans Commission (MVC)

The MVC's Service to Veterans Program, accredited Veterans Service Officers (VSO) and Veterans Service Assistants (VSA) provide counseling and assistance to thousands of veterans and their dependents throughout Missouri. These trained professionals counsel veterans on available VA and state veterans' benefits and complete and submit claims applications with all necessary documentation. Service officers and assistants are also available for any follow-up work necessary with the VA to obtain the maximum amount of earned

benefits due any eligible veterans and/or dependents. VSO/VSAs are thoroughly trained and knowledgeable in all areas of veterans' benefits, including service-connected compensation, non-service connected disability pension, education and training, vocational rehabilitation, burial, and survivor benefits. They will also assist claimants with health care eligibility, VA Home Loan Guaranty and other veterans benefits, including those offered by the state.

Phone (for benefits): 866-838-4636
Phone (Jefferson City): 573-751-3779
Website: www.mvc.dps.mo.gov

Defense and Veterans Brain Injury Center (DVBIC)

The DVBIC serves active duty military, their beneficiaries, and veterans with traumatic brain injuries (TBIs) through state-of-the-art clinical care, innovative clinical research initiatives and educational programs. DVBIC has ongoing collaboration with military, VA and civilian health partners, local communities, families and individuals with TBI.

Phone: 202-782-6345
Website: <http://www.dvbic.org/>

Missouri Department of Insurance, Financial Institutions & Professional Registration

The Missouri Department of Insurance provides oversight for insurance companies operating in Missouri. Adequate insurance for special needs individuals should contain

the following components:

- Basic medical services including physician services, preventive exams, immunizations, inpatient, outpatient, emergency room services and prescription drug benefits
- Behavioral health services (mental health services or counseling)
- Therapies (physical, occupational and speech)
- Hearing and vision services
- Affordable benefits package (co-pays, premiums, deductibles, etc.)
- Case management or service coordination

For more information regarding insurance companies offering insurance to individuals with special health care needs, call or visit the department's website (Please have individual's name, address, date of birth, diagnosis and current insurance information before calling).

Phone: 573-751-2640
Toll-free phone: 800-726-7390
Website: www.insurance.mo.gov

Missouri Department of Public Safety (MDPS)

Missouri Crime Victims' Compensation Program

The Crime Victims' Compensation Program offers help for crime victims by providing financial assistance to victims who have suffered physical harm as a result of violent crime. In the case of death, the program helps the victim's dependents. The Crime Victim's Compensation Program is designed to assist victims of violent crimes through a period of financial hardship as a payer of last resort. If a victim

has exhausted other collateral sources, such as health insurance, and has no other source of reimbursement, the program can help pay for medical costs, wage loss, psychological counseling, funeral expenses and support to a maximum limit.

Phone: 573-526-6006

Toll-free phone: 800-347-6881

Website: www.dps.mo.gov/dir/programs/cvc/

Social Security Administration (SSA)

The Social Security Administration administers Social Security Disability Income (SSDI) and/or Supplemental Security Income (SSI). If you think you may be eligible for payments, or to file a claim, contact your local Social Security Office. If you want someone to help you, such as a family member, caseworker or other representative, that person may contact the office for you.

You will get a faster decision if you provide the following:

Medical information needed for Social Security Administration:

- Names, addresses and phone numbers of all doctors, hospitals and clinics
- Patient identification (ID) numbers
- Dates seen by health care providers
- Names of medicines you are taking
- Medical records in your possession

Other information needed:

- An original or certified copy of your birthcertificate. If you were born

in another country, the SSA also needs proof of U.S. citizenship or legal residency.

- If you were in the military service, the original or certified copy of your military discharge papers (Form DD 214) for all periods of active duty.
- If you worked, your W-2 Form from last year; or if you were self-employed, your federal income tax return (IRS 1040 and Schedules C and SE).
- Workers' compensation information, including date of injury, claim number and proof of payment amounts.
- Social security number(s) for your spouse and minor children.
- Your checking or savings account number, if you have one.
- Name, address and phone number of a person the SSA can contact if they are unable to get in touch with you.
- Types of jobs and dates you worked in the 15 years prior to becoming unable to work.

You can also complete the Medical and Job Worksheet or the Adult Disability Report at: www.socialsecurity.gov/adulthooddisabilityreport. If you are filing for a child, you also need school records regarding your child's disability.

Important note: Don't wait to file your claim for disability payments even if you don't have all this information.

Phone: 800-772-1213

Website: www.socialsecurity.gov

Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention is one of the major operating components of the U.S. Department of Health and Human Services and a source of credible health information. Visit the CDC website for no cost publications about traumatic brain injury.

Toll-free phone: 800-232-4636

Website: www.cdc.gov/traumaticbraininjury/

Other Resources

Midwest Special Needs Trust (MSNT)

The Midwest Special Needs Trust provides trust services for persons with disabilities. The organization was established as a result of advocacy by parents and professionals who realized that many obstacles hinder planning for the financial future of individuals with disabilities. The organization was created by state statute (RSMo 402.199 - 402.220) in 1989. MSNT is a 501(c)(3) general nonprofit organization established for the purpose of administering special needs trusts.

Special needs trusts are a type of trust specifically designed for individuals with disabilities. If properly structured and administered, special needs trusts do not affect an individual's eligibility for benefits such as Social Security Income (SSI) or Medicaid. In addition, MSNT administers the Charitable Trust. Trust funds are used to provide assistance to individuals with

disabilities who meet eligibility and income criteria.

Toll-free phone: 888-671-1069 or 573-882-3388

Website: www.midwestspecialneedstrust.org

MPACT (Missouri Parents Act)

The Missouri Parents Act provides information on education for children with disabilities. MPACT is a statewide parent training and information center addressing all disabilities. The organization's mission is to ensure that all children with special needs receive an education that allows them to achieve their personal goals.

Toll-free phone: 800-743-7634

Website: www.ptimpact.org

Missouri Association for Community Action (MACA)

The Missouri Association for Community Action strives to provide individuals, families, and local communities at or near the poverty level, or in crisis, with essential resources and interpersonal support to move toward appropriate self-sufficiency. Call or visit the organization's website for a listing of community action agencies in your area.

Phone: 573-634-2969

Website: www.communityaction.org

First Hand Foundation

The First Hand Foundation is a nonprofit, 501(c)(3) organization supported by Cerner Corp., its associates, business partners and friends. The foundation assists individual children with health-related needs when

insurance and other financial resources have been exhausted. First Hand provides both major and minor financial assistance and strives to change the lives of children around the world, one child at a time.

Phone: 816-201-1569

Website: www.firsthandfoundation.org

Missouri Brain Injury Advisory Council (MBIAC)

The Missouri Brain Injury Advisory Council is a governor-appointed advisory council that advises the Missouri Department of Health and Senior Services on issues related to traumatic brain injury. The mission of the MBIAC is to lead in the development of a collaborative statewide system of prevention, public awareness and provision of services and supports driven by the needs of individuals with brain injury and their families. The MBIAC is made up of members from around the state representing TBI survivors and their families, health care providers, community-based providers, and state agencies.

Phone: 573-751-6246

Website: governor.mo.gov/boards/show/HEADINJU

Family Caregiver Alliance (FCA)

The Family Caregiver Alliance is a public voice for caregivers. They pioneer programs on information; education, services, research and advocacy to support and sustain the important work of families nationwide caring for loved ones with chronic, disabling health conditions.

Toll-free phone: 800-445-8106

Website: <http://www.caregiver.org/caregiver/jsp/home.jsp>

BrainLine: Preventing, treating and living with traumatic brain injury (TBI)

BrainLine is a national multimedia project offering information and resources about preventing, treating, and living with TBI. BrainLine includes a series of webcasts, an electronic newsletter, and an extensive outreach campaign in partnership with national organizations concerned about traumatic brain injury. BrainLine serves anyone whose life has been affected by TBI. That includes people with brain injury, their families, professionals in the field, and anyone else in a position to help prevent or ameliorate the toll of TBI.

Phone: 703-998-2020

Website: www.brainline.org

Brain Injury Listserves, Discussion Boards and Chat Rooms

Some people have found these avenues to be helpful in providing a convenient place to meet for support and information for people who are living with brain injury. There are many listserves, discussion boards and chat rooms in existence. Search the web for "brain injury listserves, discussion boards and chat rooms" and explore the options available.

Caution must be taken to be aware of identity theft and other potential problems if you use the internet. You should be careful when using the internet and not release any personal information about yourself that is not necessary.

Legal Resources

Missouri Protection and Advocacy (MO P&A)

Missouri Protection and Advocacy is a federally mandated system in the state of Missouri, which provides protection of the rights of persons with disabilities through legal-based advocacy. MO P&A is a member of the National Disability Rights Network (NDRN). Contact the MO P&A to learn more about their services.

Phone: 800-392-8667

Website: www.moadvocacy.org

Legal Services of Missouri

Legal Services of Missouri provides civil legal services to low income and elderly people in Missouri. You can find an office in your area on the organization's website.

Phone: 417-881-1397

Website: www.lsmo.org

Missouri Bar Lawyer Referral Service

The Missouri Bar Association offers a lawyer referral service. The service allows you to speak with an experienced staff person who will help you figure out if you need a lawyer or may direct you to other information and resources. If you need legal advice or representation, the referral service can refer you to a lawyer who practices within your geographical region and is the kind of attorney that is appropriate for your situation. The lawyer referral service is not a free service. You can find more information at:

Phone: 573-635-4128

Web site: www.mobar.org

Community Resources

Each community in Missouri is different in the types of community services that are available. You will want to check in your own city or town to find out what is offered. Your local newspaper may have a section on volunteering that will give you some ideas. Most areas have implemented a 2-1-1 system. By dialing 2-1-1, you can make a toll-free call to someone who will connect you with available community resources and volunteer opportunities. If 2-1-1 is not yet active with your phone provider, you can reach the 2-1-1 call center by dialing 800-427-4626 or visiting the website at www.211missouri.org.

Some possible suggestions for community resources to consider are:

- Meals on Wheels
- Senate Bill 40 Boards
- OATS (transportation)
- County health department
- Church or civic groups
- Community/volunteer organizations
- Co-workers
- Neighbors
- Schools

There are many useful resources on the world wide web. It would be impossible to list them all and keep them current. To find more information, resources and chat rooms that may assist you in living with traumatic brain injury, you can search by key words such as "brain injury, traumatic brain injury, or head injury" to locate many other useful websites.

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**More information about traumatic brain injury can be found at:
www.health.mo.gov/living/healthcondiseases/tbi/index.php**

**Missouri Department of Health and Senior Services
P. O. Box 570
Jefferson City, Missouri 65102-0570
www.health.mo.gov**

Hearing- and speech-impaired citizens telephone 800-735-2966. VOICE 800-735-2466.

AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYERS
Services provided on a nondiscriminatory basis..



Missouri Department of Health and Senior Services

800-451-0669

www.health.mo.gov